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Health literacy has been commonly defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (U.S. Department of Health and Human Services [HHS], 2000). However, subsequent discussions of research in health literacy have highlighted the importance of moving beyond a focus on individuals' skills to consider health literacy as an interaction between the demands of health systems and the skills of individuals (HHS, 2000; Institute of Medicine, 2004).

Health literacy now represents a substantive area of research in public health and medicine and has been recognized as an important element in the nation's health agenda. This chapter provides an overview of the health literacy literature that appeared between 2000 and mid-2005. We begin where "Health and Literacy: A Review of Medical and Public Health Literature," published in Volume 1 of the Annual Review of Adult
Learning and Literacy (Rudd, Moeykens, & Colton, 2000), left off. First, we provide a short history of the growth of the academic field of health literacy. Next we describe the methods we used to select articles, and then we discuss key research issues drawn from publications in the field.

**HISTORY OF THE FIELD**

The field of inquiry commonly referred to as health literacy has grown considerably since 2000 when “Health and Literacy: A Review of Medical and Public Health Literature” was published (Rudd et al., 2000). At the time of publication, information related to the 1992 National Adult Literacy Survey (NALS) was still new to many in the health fields and the dissemination of findings was still under way. Of primary interest to health researchers and practitioners was the principle finding that 47% to 51% of U.S. adults were limited in their ability to use print materials to accomplish everyday tasks. This statistic drew the attention of those concerned about implications for health activities and health outcomes.

Several decades of health studies in the United States, Britain, and Europe had already established strong links between health status and educational attainment or income, both commonly used as markers of socioeconomic status. However, the NALS findings highlighted the fact that literacy influences one’s ability to access information and to navigate in the highly literate environments of modern society. Analyses of health materials published before and subsequent to the NALS findings indicated a mismatch between the reading level of health materials and the average reading skills of adults. Studies in the latter half of the 1990s yielded statistically significant differences in health-related knowledge and behaviors between those with strong reading skills and those with limited skills (Rudd et al., 2000). By the turn of the century, literacy and its implications for health outcomes was the focus of a growing number of research studies in health. At the start of the new century, the National Institutes of Health called for research proposals examining components of education for possible pathways to health.

Publications in peer-reviewed journals in medicine, health education, and public health indicated interest in the health-related implications of limited literacy skills along four strands or research themes. One strand focused on assessments of the readability of print communication and the match between health materials and the skills of intended audiences. Another strand of research focused on differences between patients with strong reading skills and patients with limited reading skills related to
knowledge of disease and medical regimen, hospitalization, a variety of health behaviors, and physical markers of health status. A third strand included a growing number of studies focused on the promise for improving communication through the use of new technologies, as well as the use of icons. Finally, a fourth strand, not as fully developed as the others, focused on the development and, in some cases, the evaluation of programs designed to improve health literacy. Many of these programs considered literacy skills of the intended participants and then shaped materials or program design to more appropriately fit their needs. Some of the studies in this area focused on the effects of improvements to materials, such as substituting everyday words for medical language and jargon, and using short sentences and highlighting key points. These changes represent critical components of what is known as plain language. Other studies focused on building communication and knowledge-exchange skills and capacity within communities and among patients and providers. New research efforts are focused on numeracy and the listening and speaking skills so critical to public health communication and to the dialogue between clients or patients and a variety of health providers.

The number of studies and editorials addressing health literacy published between 2000 and the end of 2004 was more than double the number published between 1970 and 1999. A preliminary examination indicates that, to date, well over 200 articles can be found in the 2005 literature alone. Overall, the body of literature with some consideration of health literacy now consists of close to 1,000 articles. Furthermore, researchers from a broad spectrum of health fields—now including those from the oral health (dental health) and mental health fields—have published findings related to health literacy.

National conferences, white papers, and reports from prestigious agencies and academies have put health literacy on the national agenda. The growing interest in health literacy during the 1990s led to an articulation of improved health literacy as a national objective for Healthy People 2010, the 10-year health goals and objectives for the nation (HHS, 2000). Subsequently, HHS assembled scholars and practitioners to develop action plans and communication strategies for the six health communication

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35 Plain language is defined as a clear, simple, conversational style—one that presents information in a logical order.

36 Numeracy is defined as "the knowledge and skills required to effectively manage the mathematical demands of diverse situations" (from http://www.ets.org/Media/Tests/ETS_Literacy/ALLS_NUMERACY.pdf).
objectives and issued a full report, *Communicating Health: Priorities and Strategies for Progress*, in 2003 (HHS, 2003a). One chapter of that report focuses on an action plan for health literacy. The Institute of Medicine (IOM) formed a committee on health literacy in late 2002 to study the field and produce an analytic report with research, practice, and policy recommendations entitled *Health Literacy: A Prescription to End Confusion*, published by the National Academies of Sciences in the spring of 2004 (IOM, 2004). Two other important publications were issued at the same time. The Agency for Healthcare Research and Quality (AHRQ) supported an inquiry into the quality of research in this nascent field and also published its report, *Literacy and Health Outcomes*, in the spring of 2004 (Berkman et al., 2004). Researchers, one of whom was involved in the development and analysis of the NALS (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993), released *Literacy and Health in America* (Rudd, Kirsch, & Yamamoto, 2004), an examination of U.S. adults’ literacy skills in health contexts based on the 1993 NALS data. By the end of 2004, the American Medical Association published *Understanding Health Literacy: Implications for Medicine and Public Health*, a text for medicine and public health professionals, with many of the health literacy researchers responsible for key publications in the 1990s through the present day serving as section editors and chapter authors (Schwartzberg, Van Geest, & Wang, 2005). White papers from professional working groups in oral health (NIDCR Workgroup Report, 2005) and in hospital and health care oversight (Workgroup on Health Literacy and Patient Safety, planned completion in 2006) offer calls to action and delineate research opportunities.

Many governmental, professional, and local health literacy initiatives began between 2003 and 2005. For example, in 2003, the National Institutes of Health (NIH) issued requests for research proposals for more in-depth explorations of the pathways connecting literacy and health. In 2004, 13 of the NIH institutes worked together to issue and support requests for proposals specifically addressing health literacy. The Health and Human Services Office of Disease Prevention and Health Promotion convened a cross-agency workgroup on health literacy that brings together staff from across HHS, including the NIH, the Centers for Disease Control and Prevention, the Food and Drug Administration (FDA), AHRQ, Health Resources and Services Administration, Centers for Medicare and Medicaid Services, and the Indian Health Service (IHS). The purpose of the workgroup is to address health literacy, which includes developing strategies to reduce literacy-related barriers to vital health communication.
The scope of health literacy inquiry has expanded as researchers and practitioners move beyond the medical encounter to consider health-related activities at home, at work, in the community, in the policy arena, and within health systems. The HHS action plan, the IOM report, and the Educational Testing Service (ETS) analysis of health literacy all called for such an expanded inquiry. Multiple national, state, and citywide health literacy initiatives have begun, some funded by the private sector. For example, the health literacy initiative led by the Literacy Assistance Center of New York City with the Mayor’s Office of the City of New York focuses on skills adults need as they address health-related tasks at home, in the workplace, in the community, and in health care settings (Tassi, 2004).

The ETS report, *Literacy and Health in America*, offered a first look at health literacy skills through an analysis of existing health-related items drawn from large-scale surveys conducted before 2003 (Rudd, Kirsch et al., 2004). However, the 2003 National Assessment of Adult Literacy (NAAL) included a small purposive sample of health-related items, developed in cooperation with HHS. NAAL findings indicate no improvement in overall literacy skills of U.S. adults over the 1992 NALS (Kutner, Greenberg, & Baer, 2005) and even lower scores for health literacy proficiencies (Kutner, Greenberg, Jin, & Paulsen, 2006). Analyses in two different time periods indicate that large numbers of U.S. adults do not have health literacy skills that enable them to effectively use health materials to accomplish the many challenging and complex health-related tasks they encounter.

**METHODS**

To collect articles for this review update, we ran a computer-based search for relevant literature, using the PubMed, PsycINFO, and ERIC databases. We began with combinations of terms: *health, medical, functional* with *literacy, literate, illiteracy, readability, reading level, and health literacy*. We included articles from English-speaking industrialized nations. We also reviewed materials drawn from the Library of Medicine bibliography and from manual searches of journals that had published literacy and health or health literacy articles but were not yet included in the computer databases. We read the array of articles and sorted them into the four categories used in the earlier literature review:
- National reports. These reports analyze and add to previous research (covered in Rudd et al., 2000) and offer recommendations for research and policy change in the public and private sectors.
- Research on print text materials and measures.
- Research on nontext materials and measures.
- Research on health outcomes for people with different levels of reading skills.

This review, originally planned as a 5-year update, primarily offers citations from the years 2000 through 2004. However, the review was expanded into the sixth year and includes a review of articles published during the first half of 2005. Articles from 2005 are referenced insofar as they address a new area of inquiry or represent a new focus.

**Analytic Reports**

Traditionally, reviews of the literature in public health and medicine focus on articles published in peer-reviewed journals. However, this review begins with analytic reports, most of which were developed by request of governmental or national agencies and each of which report on policy implications. The purview of each of the reports, all published between the end of 2003 and the early months of 2004, is different. The HHS report presents an action plan for the health literacy objective noted in Healthy People 2010, the statement of goals and objectives for the health of the nation. The IOM report offers an assessment and overview of a newly emerging field and offers concrete recommendations for action to be taken by both governmental and nongovernmental agencies. The AHRQ report reviews and assesses the research linking literacy to health outcomes as the foundation for policy decisions. The ETS policy report provides a measure of literacy skills in health contexts and discusses implications for the education and health sectors.

**Healthy People 2010 and Communicating Health: Priorities and Strategies for Progress.** Healthy People 2010 sets forth a delineation of the national health goals and objectives for the nation covering a 10-year period (HHS, 2000). For the first time, Healthy People 2010 includes an objective to "improve the health literacy of persons with inadequate or marginal literacy skills" and action plans for the health literacy objective and the five other health communication objectives (HHS, 2000). *Communicating Health: Priorities and Strategies for Progress* (HHS, 2003a) offers an articulation of action plans for the health communication objectives.
The chapter focused on the action plan for the health literacy objective highlights the need to address characteristics of health systems, including the communication skills of professionals, institutional protocols, and print materials in common use such as health history forms, informed consent, discharge instructions, and patient education materials. The discussion of the health literacy action plan notes the mismatch between institutional assumptions and documented literacy skills of adults accessing and using health systems. Consequently, the health literacy action plan identifies key stakeholders and suggests a variety of action steps for government departments and agencies, private sector organizations, and professional associations. These include efforts to improve education, study and improve print materials, enhance communication skills among professionals, remove barriers to information and services, and decrease the complicated bureaucratic processes of health systems. Finally, the report suggests that new inquiries in health literacy expand beyond health care settings and include health actions and decisions at home, in the community, in the workplace, and in the policy arena (HHS, 2003a).

Institute of Medicine: Health Literacy—A Prescription to End Confusion. Over the course of the traditional 18-month work schedule, the IOM’s Health Literacy Committee heard testimony from a wide variety of stakeholders and addressed definitions of terms, health contexts, measurement, research findings, culture, new media, and financial implications. The report (IOM, 2004) reflects the committee’s analysis of the published research and programs, its review of the conceptual underpinnings of health literacy, and its considerations of implications for education and health policies. The report’s premise is that health literacy is an interaction between social demands and skills of individuals, and that health literacy can be improved through a combination of more realistic demands and improved skills. Consequently, the report encourages researchers and practitioners to understand, measure, and modify both the demands of health systems and the skills of professionals, as well as the skills of the public.

The IOM report also stresses the need for attention to the array of health activities within multiple health contexts, and to the broad spectrum of literacy skills that include oral exchange, numeracy, and access to and accrual of background information related to health (IOM, 2004). The IOM committee report notes that current measures do not offer a sufficient assessment of health literacy, are too narrowly focused on the ability of individuals to use the written word (rather than on a full complement of skills, which include oral communication), and do not fully capture cultural
nuances or the experiences of people with limited proficiency in English. The report highlights 18 findings and offers 15 recommendations for action that address program, policy, and research priorities directed toward various federal departments, health agencies and institutions, and the academic and private sectors.

Agency for Healthcare Research and Quality: Health Literacy and Health Outcomes. The AHRQ commissioned a report (Berkman et al., 2004) to review and assess the state of the art in health literacy and health outcome research studies. The researchers examined health literacy studies that used some measure of literacy skills and examined specific health outcomes. The review covered methods and findings of close to 50 outcome studies, many of which were published before 2000. The findings from the AHRQ report indicated that limited literacy level, as measured by approximations of reading skills, is associated with a range of adverse health outcomes, such as knowledge and comprehension (e.g., Lindau et al., 2002), hospitalization (Baker, Gazmararian, Williams, et al., 2002), global measures of health (Kalichman & Rompa, 2000; Ross, Frier, Kelnar, & Deary, 2001; Schillinger et al., 2003), and management of chronic diseases (e.g., Arnold et al., 2001; Conlin & Schumann, 2002; Kalichman & Rompa, 2000; Miller et al., 2003; Schillinger et al., 2003). However, the report recommends that covariates such as education or socioeconomic status be more thoroughly explored and notes that cross-sectional studies do not provide needed insight into change over time. Furthermore, the analysis indicates that as intervention research increased over time, further work in this area is warranted (Berkman et al., 2004).

Educational Testing Service Policy Report: Literacy and Health in America. This analysis of health literacy skills among U.S. adults (Rudd, Kirsch, et al., 2004) was based on all the health-related tasks from large-scale surveys of adult literacy. These large-scale surveys, including the NALS and the International Adult Literacy Surveys (IALS) in the United States and in Canada, were all based on the concept of functional literacy as assessed through adults' ability to use print materials to accomplish mundane tasks. All items identified as health-related were coded as belonging to one of the following groupings of health activities: health

37Findings from this review were also published in a journal article (Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004).
promotion, health protection, disease prevention, health care and maintenance, and navigation of health systems. The resulting 191 items were assembled as the Health Activities Literacy Scale and then linked to the demographics of the 26,000 adults participating in the NALS. Mean health literacy scores were calculated by gender, education, minority status, nativity, age, and access to resources through a link to the NALS database. The report, *Literacy and Health in America* (Rudd, Kirsch, et al., 2004), indicates that approximately 47% to 51% of U.S. adults have low or limited literacy skills. Limited literacy proficiency is generally associated with lower educational attainment, presence of health-related restrictions (health problems that limit participation in work or school), minority or immigrant status, and lack of access to resources. Findings indicate that large percentages of vulnerable or at-risk groups do not have adequate skills to meet many of the health-related demands they are likely to encounter. The differences within and among various population groups with different levels of literacy proficiencies indicate powerful effects of social factors (Rudd, Kirsch, et al., 2004). The report, a first look at health literacy based on a national assessment, suggests changes in the education and health sectors and notes the importance of a collaborative effort between the two.

**Common Issues**

Each of the reports addressed issues related to the scope and measurement of health literacy, all noting the promise of early studies in health literacy that linked reading skills and health outcomes. All call for a broader scope of inquiry and for studies that continue to include—but also move beyond—the doctor–patient encounter, including investigations into health-related activities at home, in the workplace, in the community, and in a range of health systems and care settings.

In addition, each of the reports notes the importance of attention to the broad range of literacy skills, and highlights the need to examine math skills as well as the oral and aural language skills that are so important for public health announcements, media communication, and patient–provider exchanges. All of the reports concur that measures of health literacy now commonly used in research settings do not actually measure health literacy, but instead offer approximations of reading skills. Consequently, each report calls for the development of health literacy measures that address reading, writing, basic math, and oral language skills. The analyses also suggest that researchers more closely examine patients’
information-seeking skills, consider the importance of background knowledge for health-related activities, and study the value of new technologies such as interactive computer programs, touch-screen technologies, voice components, DVDs, and the Internet. Furthermore, the IOM report urges researchers and practitioners to pay attention to culture and cultural differences and to prevailing and, perhaps, faulty assumptions about adults’ background knowledge and experience. Finally, all of the reports identify issues related to policy, regulations, and research procedures and offer recommendations for change or new developments.

TEXT

The health literacy literature from 2000 through early 2005 includes examinations of health-related texts, print materials used for research tools and instruments, and health information posted on Web sites. The research findings indicate that health information continues to be written at levels of complexity that exceed the skills of average high school graduates. This mismatch has been documented for educational materials, instructions, informed consent, research instruments, and public health information and warnings about known dangers and hazards. Research findings also indicate that neither medical nor public health materials adequately prepare people to take needed action or to make informed decisions.

Most studies of print materials report use of a small variety of tools to assess the readability of materials. These tools include those for assigning a reading level to print materials, such as the SMOG Readability Formula (McLaughlin, 1969), FRY Formula (Fry, 1977), and the Flesch Reading Ease Formula (Flesch, 1948). Broader assessment tools, such as the SAM (Doak, Doak, & Root, 1996), look at reading-level calculations, as well as the organization and design of text, such as use of headings, font, white space, visuals, and cultural appropriateness. A few published assessments include the PMOSE/I KIRSCH (Moseithal & Kirsch, 1998), a tool for assessing the level of complexity of the structure of “documents”—those materials formatted as lists, charts, and graphs.

New Assessment Measures and Focus

Most of the published studies in health literacy focus on assessments of health materials. These inquiries set the foundation for health literacy studies and, starting from the mid-1960s, provided evidence of the “high demand"
of health materials on literacy skills (Rudd et al., 2000). Such studies continue to be published as researchers examine literature from a wide range of health-related fields. In addition, researchers are expanding the analysis of materials to include examinations of research and survey instruments and commonly used psychosocial measurement scales, as well as a variety of information posted on Web sites. Findings remain consistent and indicate that health information continues to be written at levels of complexity that exceed the skills of average high school graduates. For the most part, this body of literature uses a reading grade level as an indicator of the level of difficulty of existing text. One study reports on the process of assessing materials (Harvey & Fleming, 2000), and another on the process of assessing and rewriting materials (Rudd, Kaphingst, Colton, Gregoire, & Hyde, 2004). Two studies focus on processes and tools for assessing materials posted on the Internet (Bernstam, Shelton, Walji, & Meric-Bernstam, 2005).

Research Instruments

The well-documented mismatch between the reading levels of health-related materials and NALS findings of adults’ ability to use text found in everyday life spurred interest in medical and research concepts, instruments, and processes.

Literacy-related barriers could influence participation in research studies and compromise data, as well as confound analysis. For example, informed consent is linked to all research efforts. Studies indicate a longstanding mismatch between the reading demand of consent forms and the reading skills of average high school graduates. Kubba (2000) found that the reading skill level of otolaryngology patients under study was lower than the reading level of information leaflets, admission notification letters, and surgical consent forms in use. Cox (2002) found that patients did not understand the informed consent materials for a cancer clinical trial. Conlin and Schumann (2002) found that the reading skill levels of open-heart-surgery patients were lower than the reading level of informed consent forms and discharge instructions. Gausman Benson and Forman (2002) found that informed consent forms were too complicated for affluent geriatric patients in their study. Finally, an examination of materials provided by institutional review boards indicated that they commonly provide text for informed consent materials that is written at reading levels that are too high and do not meet their own readability standards (Paasche-Orlow, Taylor, & Brancati, 2003).
Several studies indicate that many types of research instruments should be examined for literacy-related barriers. For example, Sentell and Ratcliff-Baird (2003) found less comprehension of the Beck Depression Inventory\(^\text{38}\) among those with limited reading skills. Woloshin, Schwartz, Moncur, Gabriel, and Tosteson (2001) found that those with limited reading skills were less likely to understand risk–benefit analyses. These studies indicate that health measures that assume critical concepts are being widely understood may be assessing literacy skills instead of the main variable of interest.

**New Technologies**

A number of studies looked beyond booklets and pamphlets to explore new communication approaches, including the Internet, multimedia computer software, and the use of touch-screen technology to communicate health information to patients with low health literacy skills. The use of a computer and access to the Internet must still be considered print material and would not, of course, increase access to information if the materials are written at levels beyond the average reading skills of the public.

Several studies reported on the readability and accessibility of health-related information on the Internet and indicate that sophisticated reading skills are needed to access and comprehend Web-based health information (Berland et al., 2001; D’Alessandro, Kingsley, & Johnson-West, 2001; Friedman, Hoffman-Goetz, & Arocha, 2004). Birru and colleagues (2004) discussed the importance of having health information on the Internet written at low reading levels, and with culturally appropriate references. Furthermore, studies do not yet indicate whether use of computers enhances or diminishes people’s ability to locate needed information.

Some researchers have experimented with the use of touch-screen technology to bypass some of the difficult aspects of computer use. Hahn and colleagues (2004) discussed the use of a “talking touch screen” as a practical, user-friendly data acquisition method that allows providers to measure self-reported outcomes in patients with a range of literacy skills.

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\(^{38}\)The Beck Depression Inventory (BDI, BDI-II), created by Dr. Aaron T. Beck, is a 21-question multiple-choice survey that is one of the most widely used instruments for measuring depression severity (http://en.wikipedia.org/wiki/Beck_Depression_Inventory).
Lobach, Arbanas, Mishra, Campbell, and Wildemuth (2004) reported on the development of a computer system that uses touch-screen technology to gather health information from patients with low literacy skills and has implications for both educating patients and research applications. This computer system is being used in an academically affiliated family medicine clinic and in an indigent adult medicine clinic; study findings are not yet available.

Beyond the Printed Word

A small but accumulating body of literature includes the study of materials that use symbols, cartoons, and pictograms for communicating critical health and medical information. Approximately 20 studies have examined outcomes associated with specific low-literacy materials that include use of pictographs, videos, and interactive multimedia software, as well as comic books. For example, a number of studies indicate that pictographs used in medicine labels and medical instructions have helped patients increase their knowledge (Houts, Witmer, Egheth, Loscalzo, & Zabora, 2001). Mansoor and Dowse (2003) reported that pictograms on medicine labels and patient information leaflets had a positive effect on patients’ acquisition and comprehension of drug information. Leiner, Handal, and Williams (2004) reported on the increased effectiveness of using cartoons over text-based materials for delivering information about polio vaccinations to patients. However, Hwang, Tram, and Knarr (2005) found that commonly used illustrations on medicine labels were of little or no use in improving patients’ comprehension of the medication for patients under study.

Examinations of the use of videos indicate increased understanding among patients viewing videos compared to patients using print materials. These studies include use of videos or interactive software products for prostate cancer treatment (Diefenbach & Butz, 2004; Rovner et al., 2004), for breast cancer screening among Latinas (Borrayo, 2004), for sleep disorders (Murphy, Chesson, Walker, Arnold, & Chesson, 2000), and for polio vaccines (Leiner et al., 2004).

MEASURES OF LITERACY SKILLS

Most of the researchers in the published literature linking patient or client skills to health outcomes use one of two commonly used measures: the Rapid Estimate of Adults’ Literacy (REALM) or the short form of the Test
of Functional Health Literacy in Adults (TOFHLA). Both of these instruments, developed in the 1990s, were discussed at length in the first review of the literature (Rudd et al., 2000). The REALM is based on a word recognition test and the short form of the TOFHLA on a cloze-style reading comprehension test. Both tests can be administered in a brief period of time in medical and research settings. In addition, both tests correlate well with each other and with other tests of reading skills and have been used effectively to distinguish between groups of patients with varying levels of reading skills and a variety of health outcomes. However, the IOM, AHRQ, and ETS reports concur that these tools offer approximations of reading skills and do not test health literacy.

ETS developed a computer-based test, the Health and Literacy Survey, a 30-minute assessment of adult literacy skills in health contexts (ETS, 2005). They developed this tool in late 2004 after the publication of the ETS report. It is based on items from the large-scale assessments of adult literacy, including the NALS, IALS, and the NAAL, and can be linked to national measures. Most recently, Weiss (2005) announced the development of a new and short tool, *The Newest Vital Sign*, resembling the material and question format used in the NALS and NAAL. The instrument allows a researcher to determine a patient’s document literacy skills.

**HEALTH OUTCOME STUDIES**

New developments in examinations of health outcomes over the course of the past 5 years include measures of differences between those with more limited reading skills and those with strong reading skills (as assessed by the REALM or the short form of the TOFHLA) for knowledge and understanding of a variety of health-related concepts such as risk, probability, or chronicity (Arnold et al., 2001). Similarly, several studies document that an understanding of chronic diseases and of associated treatment protocols is related to reading skills (Gazmararian, Williams, Peel, & Baker, 2003; Kalichman et al., 2000; Kalichman & Rompa, 2000; Van Servellen, Brown, Lombardi, & Herrera, 2003). Two studies found that patients with poor reading skills had poorer physical and mental health compared to those with stronger skills (Gazmararian, Baker, Parker, & Blazer, 2000; Sentell & Shumway, 2003). Findings indicate that participants with lower reading skills are less likely than those with stronger skills to engage in health-promoting behaviors (Kaufman, Skipper, Small, Terry, & McGrew, 2001), to engage in screening programs (Davis et al., 2001; Dolan et al.,
HEALTH LITERACY

2004; Fortenberry et al., 2001; Lindau et al., 2002), or to access appropriate health care (Baker et al., 2004; Pirisi, 2000; Scott, Gazmararian, Williams, & Baker, 2002). In addition, patients with limited reading skills are less likely to follow preoperative instructions (Chew, Bradley, Flum, Cornia, & Koepsell, 2004) or to be compliant with breast cancer treatment protocols (Li et al., 2000), and are more likely to be hospitalized than are those with strong reading skills (Baker, Gazmararian, Williams, et al., 2002; Gordon, Hampson, Capell, & Madhok, 2002).

Study findings link reading skills to biological change and disease burden as well. Several research publications indicate that study participants with poor reading and numeracy skills, compared to those with stronger skills, have worse anticoagulation control (Estrada, Martin-Hryniewicz, Peek, Collins, & Byrd, 2004) and worse control of diabetes (Endres, Sharp, Haney, & Dooley, 2004; Kim, Love, Quistberg, & Shea, 2004; Schillinger et al., 2002). Diabetes research indicates that diabetic children between the ages of 5 and 17 had poorer glycemic control if their parents had limited reading skills (Ross et al., 2001).

Other research studies document decreased cognition (Baker, Gazmararian, Sudano, et al., 2002a; Barnes, Tager, Satariano, & Yaffe, 2004) and increased levels of depression or other mental health issues (Gazmararian et al., 2000; Sentell & Shumway, 2003) among patients with limited reading skills compared to others with stronger skills. Several studies document increased rates of cervical cancer among those with more limited reading skills (Lindau et al., 2002; Sharp, Zurawski, Roland, O'Toole, & Hines, 2002).

Costs associated with literacy are often considered another outcome variable. Three reports indicate an increased cost to the health system (Baker et al., 2004; Howard, Gazmararian, & Parker, 2005; Weiss & Palmer, 2004). Howard and colleagues (2005), for example, concluded that persons with inadequate health literacy incur higher medical costs and use an inefficient mix of services. However, the IOM (2004) report concluded that no studies to date have differentiated costs linked to patient literacy and costs associated with medical errors. Thus, there might not yet be sufficient evidence to associate a particular cost with patient literacy level.

NUMERACY

The national and international surveys of adult literacy included assessments of quantitative or numeracy skills. Policy recommendations in the
HHS and IOM reports, noted earlier, call for attention to a full range of literacy skills in health contexts, including quantitative skills, as do several health researchers (Woloshin et al., 2001; Zarcadoolas, Pleasant, & Greer, 2005). Such skills are needed for day-to-day health-related activities, including comparison shopping, discounting, measuring, calculating, dosing, and scheduling and timing of medicine (Rudd, Kirsch, et al., 2004). Woloshin and colleagues (2001) measured numeracy skills among a group of volunteers and concluded that limited numeracy skills may be an important barrier for patients who are asked to make decisions based on an understanding of risk and probability. One of the mandated responsibilities of public health practice is to alert the public to dangers and hazards based on risk assessments. Practitioners and researchers have been remiss in their ability to provide such information and continue to use problematic texts and complex calculations (J. Hyde, personal correspondence, 2005). Golbeck, Ahlers-Schmidt, Paschal, and Dismuke (2005) proposed a distinct definition of health numeracy to spur additional research in this area.

CONTRIBUTIONS OF VARIOUS DISCIPLINES

Over the past 5 years, research in health literacy has expanded beyond examinations of the medical encounter and now includes more papers from professionals involved in public health, health education, oral health, mental health, and nursing. Attention to health literacy among a broader group of professionals is indicative of how interest in the topic has spread. To date, health literacy research in fields such as public health, pharmacy, occupational health, and social work has been relatively sparse when compared to publications in medicine; however, the numbers of such studies are increasing. In addition, researchers in public health, oral health, mental health, nursing, and pharmacology report testing direct interventions that promote better health communication.

Public Health

Few public health studies, beyond those focused on screening noted previously, examine literacy-related barriers to access of public health information. At the same time, public health literature has traditionally included attention to diffusion of information, communication efforts, and the design of specific messages. Communication failures have been linked
to poor design of materials or text, insufficient piloting, and, only recently, to lack of attention to literacy-related issues. Two studies report attempts to assess and reduce the reading demand of public health materials such as brochures about water safety sent to all households in a state (Rudd, Colton, Das, DeJong, & Hyde, 2003; Rudd, Kaphingst, et al., 2004). Another study focused on health alerts concluded there is a need for increased rigor in the development of official announcements. For example, the anthrax-related postcard sent to all households in the country by the Postmaster General, one of only two national household mailings on health, masked critical health information with the use of unnecessarily cumbersome terms. Researchers argue that information provided during times of crisis must be developed and designed with rigor, and in plain language, to assure clear communication (Rudd, Comings, & Hyde, 2003). Zarcadoolas and colleagues (2005) similarly noted the need for clear communication in times of crisis and, most especially, instances of bioterrorism.

**Oral Health**

The Surgeon General’s *National Call to Action to Promote Oral Health* (HHS, 2003b) notes that all stakeholders should work together and use data to enhance oral health literacy. To date, however, the majority of oral health studies pertaining to health literacy have addressed the paucity of educational resources written in plain language suitable for audiences with average or limited literacy skills (Alexander, 2000; Chestnutt, 2004). One study noted that the recognition of oral health problems and directives for oral health care may be linked to adults’ ability to understand information provided (Gaston, 2002). Thus far, the published literature linking oral health and literacy is sparse (Williams, 2004). A working group white paper and several articles and editorials published in 2005 do call for more attention to oral health literacy, research, and intervention development and implementation (NIDCR Workgroup Report, 2005; Rudd & Horowitz, 2005a, 2005b).

**Mental Health**

Literacy research in the field of mental health has been less rooted in materials development and more centered on outcomes-based research, measurement issues, and the effects of mental health literacy. Research
includes a focus on the extent to which limited health literacy may serve as a contributor to poor mental health status (Gazmarian et al., 2000; Sentell & Shumway, 2003). Studies have also addressed the extent to which results from existing measurement tools used in mental health research and practice (e.g., the Beck Depression Inventory and the Mini Mental State Examination) may be confounded or skewed by respondents' limited literacy skills (Baker, Gazmarian, Sudano, et al., 2002; Sentell & Ratcliff-Baird, 2003).

In addition, research in the mental health field introduces the concept of mental health literacy as a term used to describe knowledge and understanding of mental health issues specifically (Goldney, Fisher, & Wilson, 2001; Forn, 2000). The concept of mental health literacy is focused on the content of mental health information and not on the functional skill needed to engage in mental health actions. Mental health literacy, or lack thereof, has been used as a possible factor to explain uncertainties or lack of knowledge about mental health and the ensuing effects on effective treatment and care. The degree to which mental health literacy as a separate and slightly altered concept will be integrated into subsequent research and practice has yet to be seen, and will presumably have significant implications for the tone and direction of future research in this field.

Nursing

Nurses have long played a role in patient education, and the nursing literature has been attentive to issues related to education background and increasingly, to literacy (Routman, 2004). Many articles in the nursing literature mentioning education or literacy focus on the suitability of both print (Galloway, Murphy, Chesson, & Martinez, 2003; Winslow, 2001) and Internet-based patient information (Oermann & Wilson, 2000). Some studies have assessed the general importance of lower reading level materials; others link the importance of reading skills for specific health content areas such as cancer prevention or cardiovascular care (Chelf et al., 2001; Conlin & Schumann, 2002; Wilson, Baker, Brown-Syed, & Gollop, 2000). Some research includes a focus on nurse-patient communication and the oral exchange (Alspach, 2004; Glanville, 2000).

Although most health literacy studies conducted by and for nurses have focused primarily on raising awareness, several discussion papers offer insights on how nurses can be involved in more tangible change through materials design (Horner, Surratt, & Juliusson, 2000; Ross, Potter, & Armstrong,
2004) and intervention development (Evers, 2001; Mayer & Villaire, 2004; Wydra, 2001). Given the enormous growth of literature on nursing and health literacy, it is expected that this field will continue to be a major contributor to health literacy and will play an increasingly critical role in translating health literacy research into practice.

**Pharmacology**

Recent pharmacology research has contributed to the body of literacy focused on the readability levels of printed health resources, specifically, medication package inserts and other direct-to-consumer drug information (Hochhauser, 2002; Kirksey, Harper, Thompson, & Pringle, 2004). Literature in this field highlights the importance of written materials for the proper use of medicine and the ways that the written materials may limit or support treatment and adherence (Koo, Krass, & Aslani, 2003; Mansoor & Dowse, 2003). Several editorials and articles highlight the particular role played by pharmacists and the assistance they could offer in encouraging medication adherence. These articles focus on the critical need for pharmacists to consider health literacy as they talk with patients (Nichols-English & Poirier, 2000; Youmans & Schillinger, 2003).

An article by Rothman and colleagues (2004), for example, addresses the responsibility of pharmacists who can provide a bridge between patients’ limited literacy skills and successful medicine use. Findings indicate that diabetes patients educated by pharmacists maintained better glycemic control. However, Praska, Kripalani, Seright, and Jacobson (2005) reported that community-based pharmacists may not be attentive to the needs of patients with limited literacy skills.

The published literature related to pharmacology indicates a growing interest in medicine labels, patient package inserts (PPIs), and advertising. Ross and colleagues (2004) developed and field-tested a PPI for oral contraceptives that the FDA will soon be using. PPIs for oral contraceptives were previously written at 10th- and 12th-grade reading levels; this new PPI is written at a 6th-grade reading level. Emerging research topics in this field include attention to speakers of other languages. For example, Leyva, Sharif, and Ozuah (2005) reported that medicine labels were difficult for Spanish-speaking patients with limited English proficiency to read and understand.

Prescription drug information developed for print format and television advertisements has drawn attention as well. For example, Kaphingst and colleagues examined direct-to-consumer advertisements for prescription
medications and found that the available print materials are too complicated for adults with average literacy skills (Kaphingst, Rudd, DeJong, & Daltroy, 2004). This same research team also reported that consumers with limited literacy skills recalled the benefits of drug information presented in television advertisements, but not the risks (Kaphingst, Rudd, DeJong, & Daltroy, 2005).

Efficacious and Innovative Approaches

Researchers have studied brochures and booklets that use plain language and are written at reading grades below high school levels for a wide range of public health issues, such as immunizations (Evers, 2001), hepatitis (Wilson, 2003), breast self-exams (Coleman et al., 2003), and diabetes care (Echeverry, Dike, Washington, & Davidson, 2003). In most instances, materials more appropriately matched with the reading skills of the intended audience have been associated with healthful outcomes, such as decreased emergency department visits (Herman & Mayer, 2004) and decreased anxiety (Coyne et al., 2003).

One study of vaccine information combined videos with the use of brochures and found an increase in the likelihood that patients would talk with providers about vaccines and then receive a vaccination (Thomas et al., 2003). Borrayo (2004) reported on the use of a video in a soap opera format to create awareness about breast cancer and to motivate low-literacy Latinas to have mammograms. Rossi, McClellan, Chou, and Davis (2004) found that ankle fracture surgery patients who watched a video before signing a consent form were more likely to understand the surgery than those who only received a verbal explanation of the surgery. One article focused on the development of an asthma glossary of terms to help patients with asthma access print materials with greater ease and suggests that companion materials such as glossaries may help patients engage more easily in discussions with caregivers (Rudd, Zobel, et al., 2004).

Elkind, Pitts, and Ybarra (2002) reported that a one-act Spanish play in Washington State enacted by a community players' group increased participants' positive knowledge about farm health and safety. In another innovative use of media, Rich (2004) found that videos developed by children and adolescents provide clinicians with insight into patient health issues perhaps beyond what the patients may have been able to offer orally. Communications that use audio and visual components may prove promising for people with limited literacy skills.
Materials developed in Canada and in the United States have been designed to help professionals improve health literacy. Examples may be found in the Canadian National Literacy and Health Program (in association with the Canadian Public Health Association), which offers a Plain Language Service that provides plain language and clear design assessments and revisions, as well as focus testing and workshops for the public, private, and voluntary sectors for health products intended for the general public (Canadian Public Health Association, 2005). In addition, the program’s Health Resources Centre continues to publish materials and guidelines that incorporate plain language approaches for work with seniors and others with low literacy skills. In the United States, the American Medical Association used video segments from tapes accumulated in medical practices in Louisiana and Georgia to develop a video and accompanying materials for medical practitioners interested in learning about health literacy and techniques for working with patients who have low literacy skills (Weiss, 2003). Researchers with the National Center for the Study of Adult Learning and Literacy developed professional development programs for adult educators interested in teaching health literacy skills (Rudd et al., 2005). Finally, marking new potentials for greater ease in research studies, Kalichman and colleagues (2005) reported on the use of a visual analog scale, with pictographs, for a measure of medication adherence efficacy.

CONCLUSIONS

The body of literature and research addressing health literacy in the first 5 years of the new century has exponentially expanded the scope and depth of the knowledge base about health literacy. Published studies in health outcomes continue to address important concerns related to comprehension and knowledge, but also include sophisticated physical measures related to disease control or lack thereof. Published studies about materials assessment have moved beyond calculations of reading levels and now include closer examinations of organization, primacy of information, language, sentence structure, and layout and design elements. Researchers and practitioners are examining documents (materials in the form of lists, charts, and graphs) as well as prose (materials in full sentences in paragraph format), and are testing the match between the demands of materials and the skills of the intended audiences. Furthermore, new studies are focusing on materials and communication channels that move beyond
the printed word. Similarly, new developments in implementation studies enable educators and clinicians to consider materials as vehicles of information exchange, as well as tools for completing health-related tasks. Studies are also examining the effects of these materials on behaviors of both health professionals and patients as they interact with one another.

Articles now published in a wide variety of professional journals indicate that many health professional groups have begun to pay attention to literacy-related issues and literacy-related barriers to action, care, and services. Professionals from multiple health-related disciplines have been examining the materials they develop and use, the match between the reading level of materials and the skills of the intended audiences, the links between literacy-related skills and a variety of health outcomes, and the links between literacy-related skills and health disparities.

At the same time, gaps are evident. Few studies focus on the communication or understanding of basic math skills related to complex mathematical concepts of risk and probability. Studies to date have not addressed the wider range of literacy skills that include oral comprehension and oral presentation—skills of particular interest for public health communications and for an understanding of the dialogue between clients or patients and service or health providers. Researchers have not yet examined the links between literacy or health literacy skills and documented health disparities among population groups in the United States. Few studies have looked at literacy issues in research settings—either the barriers to be found in the language and structure of commonly used measures or the effect of complex informed consent language for recruitment among minority population groups. Finally, the full potential for innovative use of computers has not been addressed or studied. For example, few, if any, computer programs or Internet sites on health topics include voice options or online glossaries.

The literature does indicate a change in perspective. During the 1990s, many health professionals evinced concern with reading deficits among adults, implying that the lack of reading skills alone explained problems such as lack of comprehension or inability to follow a regimen. Current articles indicate growing awareness of a shared responsibility in the communication process, and of literacy-related barriers in the health care environment (Rudd, 2004). Furthermore, the Healthy People 2010 Action Plans to achieve the health communication objectives (HHS, 2000) note clearly that the skills of health professionals, the use of jargon and technical language, and the complications of bureaucratic processes affect
health literacy. Similarly, the IOM (2004) report on health literacy highlights that dual responsibility and indicates that health literacy is a shared function of social demands and individuals' skills.

Improvements in health literacy, suggested by both of these reports, require change within health systems and among health professionals, as well as changes in the skills of U.S. adults. Findings from the 1992 NALS (Kirsch et al., 1993) drew the attention of the health sector. The first publication of findings from the 2003 NAAL at the end of 2005 added additional confirmation of the 1992 findings, indicating little if any change over the course of 12 years. The health literacy literature indicates that improvements in health may well be linked to stronger investments in education in both the K–12 and adult education sectors.

The Healthy People 2010 and IOM reports identify critical stakeholders and partnerships that could be forged to improve health literacy. Links between adult education professionals and health professionals are specifically highlighted. Such partnerships can lead to mutual learning and contribute to improvements in both health literacy skills of the public and literacy-related demands within health systems.

REFERENCES


