

The Invisible Barrier: Literacy and Its Relationship with Oral Health

A Report of a Workgroup Sponsored by the National Institute of Dental and Craniofacial Research, National Institutes of Health, U. S. Public Health Service, Department of Health and Human Services

Abstract

Although oral health in the United States has improved significantly over time, preventable and treatable oral diseases remain common, especially among the poor and underserved. Limited literacy skills among adults are hypothesized to be one of many barriers to better oral health outcomes. Adults must be able to understand, interpret, and act on health information, whether it is communicated in spoken or in written form, to maintain their oral health and manage disease. While the body of health literacy research has grown in recent years, little is known about oral health literacy. Research is needed to build an understanding of oral health literacy and its impact on a variety of outcomes, including adoption of effective disease prevention regimens and actions, adherence to treatment regimens, effectiveness of caregivers and ultimately, improved oral health status. In addition, the effect of oral health literacy on the validity of clinical research such as response to surveys and adherence to research protocols is another area that is important to investigate.

This paper defines oral health literacy and offers a framework for studying relationships between oral health literacy and other points of intervention for improving health outcomes. Findings of existing health literacy research are summarized, and a research plan for oral health literacy is proposed. A broad-based collaborative effort will be required to develop a detailed agenda for research, one that is aimed at reducing literacy barriers to oral health and ensuring that the information and insights emanating from new oral health research are more widely adopted.

Key words: oral health, dental health, literacy, health literacy, health communications

Introduction

Oral health (1) is an integral part of overall health and well-being. As stated in *Oral Health in America: A Report of the Surgeon General*, "Just as we now understand that nature and nurture are inextricably linked, and mind and body are both expressions of our human biology, so, too, must we recognize that oral health and general health are inseparable. . . . No one can be truly healthy unless he or she is free from the burden of oral and craniofacial diseases and conditions (2)."

Oral diseases are not only a major cause of infection and tooth loss; they can cause debilitating pain and difficulty with eating and speaking, as well as limit social interactions. Furthermore, the impact of oral disease is not confined to the mouth. New research indicates that there are associations between chronic oral infections and heart and lung diseases,

diabetes, stroke, and pre-term low birth weight (2). However, thanks to advances in prevention and treatment, oral health in the United States is better today than ever before. Community-wide approaches, such as community water fluoridation and efforts to increase public awareness of the importance of oral hygiene, have been highly effective in improving oral health. Provider-based interventions such as the application of dental sealants and topical fluorides to prevent tooth decay and the use of antibiotics to treat oral infections also have been effective.

Yet despite these gains, preventable and treatable oral diseases remain widespread, particularly among poor and underserved populations. The incidence of untreated oral diseases and problems is disproportionately high among those populations with lower incomes and less

education, the uninsured and underinsured, the elderly, and racial and ethnic minorities. Consequently, the U. S. Surgeon General has referred to dental and oral diseases as a "silent epidemic" affecting our most vulnerable citizens.

There are many reasons why preventable oral diseases remain so common and why people often do not adopt practices that have been scientifically shown to be effective in maintaining oral health (3). Financial issues are most frequently cited and additional issues range from a lack of access to providers and adequate preventive care to a spectrum of biological, behavioral, community, and cultural factors. While recognizing their importance, this paper does not attempt to address all of these influences. Rather, the focus here is on literacy—specifically, *oral health literacy*—which we believe to be an important determinant of oral health, one that intersects with other determinants in myriad ways. Literacy is certainly not the only pathway to better oral health outcomes, but it is an important avenue that any effort to improve oral health outcomes must take into account.

Over time, literacy skills have increasingly become a currency for success at home, at work, and in the community (4). Research indicates that this is true within health contexts as well (5-6). To maintain oral health and manage disease when it occurs, one must be able to understand, interpret, and act on health information, whether it is communicated verbally or in written form. An individual's skills are only one part of the equation. Complex and complicated communications tax existing skills and erect an unnecessary barrier. Oral

health communications (brochures, forms, and providers' explanations of procedures and treatments, for example) are often dense, unnecessarily technical, and full of jargon, obscured by words like "pharynx," "orally," "occlusal" and "contraindications" instead of more familiar terms used in everyday speech. As a result, these communications are often difficult to understand, especially for individuals with limited literacy skills. This situation creates a significant barrier to improved oral health, exacerbating other barriers such as those related to economics, insurance coverage, and access.

As the title of this paper suggests, the literacy barrier to oral health is largely invisible because it is seldom recognized and little understood. Many health practitioners are ill-prepared to understand and address the literacy needs of their patients and so they may present information without checking to be sure that their presentation is clear and that communication has been successful. They also tend to use readily available materials, which may be difficult to understand. Few patients are willing to reveal that they have trouble understanding a professional's presentation or that they do not know a term that appears to be known by others. Furthermore, many patients are uncomfortable asking questions or requesting additional explanations.

The problem of limited literacy is also invisible because many of those whom it affects do not perceive that they have a problem. For example, national literacy survey data show that among those adults who display the most limited literacy skills, 71 percent of them describe themselves as having no difficulty with reading or writing (4). Of course, many of these adults may have already limited their exposure to print and so may not recognize limitations in their skills. Others realize that they are struggling but, because of discomfort, take great pains to conceal it. Elaborate coping strategies may hide their struggles even from members of their own families (7). Yet they are left unable to reap the benefits of available information,

are vulnerable to errors resulting from misunderstanding and misinterpretation, and suffer consequences, sometimes with devastating results.

National awareness of the importance of literacy for health-related tasks and activities has grown over the last several years. This awareness has been fueled by concerns about public health communication, disparities in access to care and services, possible violations of patient rights and responsibilities, and by a desire for active partnerships between patients and providers. Accordingly, numerous publications by government

agencies and other organizations have underscored the need to focus on literacy's role in improving or diminishing health outcomes (5-6, 8-9).

While the body of health literacy research has been growing, we know very little at present about *oral health literacy*. Recognizing this urgent need for information, the National Institute of Dental and Craniofacial Research (NIDCR) convened a Working Group on Functional Oral Health Literacy in January 2004. The workgroup included dental and non-dental participants (Figure 1.) Using what has been learned in the health literacy field as

FIGURE 1
List of workshop participants and their affiliations

Cynthia E. Baur, PhD	Department of Health & Human Services, Office of the Secretary, Office of Disease Prevention & Health Promotion, Rockville, MD
John P. Comings, EdD	National Center for the Study of Adult Learning and Literacy Harvard Graduate School of Education, Boston, MA
Caswell Evans, DDS, MPH	College of Dentistry University of Illinois at Chicago, Chicago, IL
Raul Garcia DMD, MMSc	School of Dental Medicine Boston University, Boston, MA
Alice M. Horowitz, PhD	National Institute of Dental & Craniofacial Research National Institutes of Health, Bethesda, MD
Amid I. Ismail, BDS, MPH, DrPH	Department of Cariology, Restorative Sciences & Endodontics School of Dentistry, University of Michigan, Ann Arbor, MI
Dorry M. Kenyon, PhD	Language Testing Division Center for Applied Linguistics Washington, D.C.
Irwin S. Kirsch, PhD	Center for Global Assessment Educational Testing Service Princeton, NJ
Dushanka V. Kleinman, DDS, MScD	National Institutes of Health U.S. Public Health Service Bethesda, MD
Rima E. Rudd, MSPH, ScD	Department of Society, Human Development, and Health Harvard School of Public Health, Boston, MA
John Strucker, EdD	National Center for the Study of Adult Learning and Literacy Harvard Graduate School of Education, Boston, MA
George W. Taylor, DMD, MPH	School of Dentistry, University of Michigan Ann Arbor, MI
Katherine K. White, PhD	Department of Psychology College of Charleston, Charleston, SC

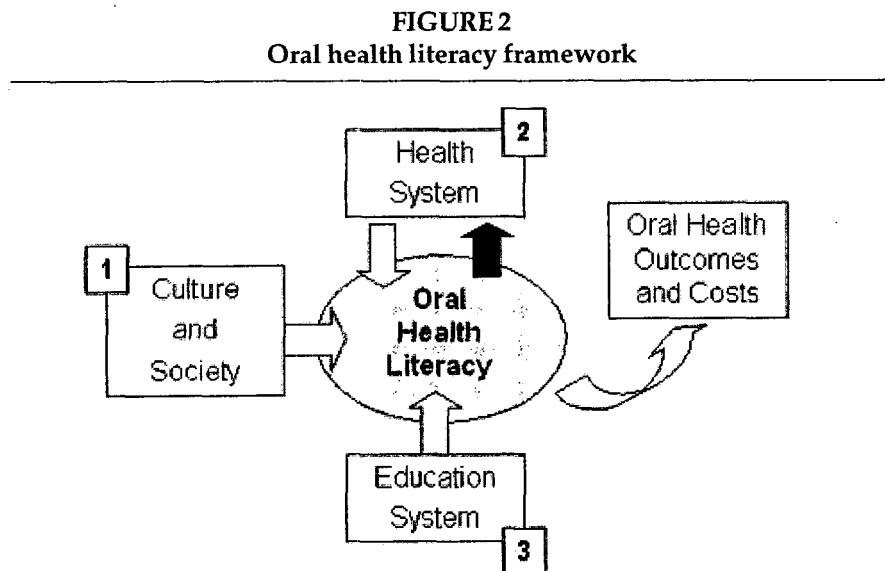
a foundation, the working group focused on a research plan that will build an understanding of oral health literacy and its impact on a variety of outcomes—for example, adoption of effective disease prevention methods, successful adherence to treatment regimens, and ultimately, improved oral health status. In addition, the potential impact of oral health literacy on clinical research was acknowledged.

Although it is beyond the scope of our short-term collaboration to define a detailed agenda for oral health literacy research, we recommend that a task force be formed to undertake this crucial task. As we envision it, a group composed of oral health professionals and researchers, as well as experts in health literacy, would collaborate over an extended period of time to summarize what is known about health literacy from the perspective of dental health professionals, and building on this, to delineate the types of studies and assessment tools that are needed to build a knowledge base about oral health literacy. This body of work is urgently needed to inform the efforts of policy makers, providers, adult educators, researchers and others who are invested in improving oral health for all.

This white paper sets the stage for that ambitious undertaking. It begins by considering contributions to oral health, defining oral health literacy and then presenting a framework that is useful in thinking about how oral health literacy relates to other possible points of intervention for improving health outcomes. Findings of existing research on health literacy are briefly summarized. Finally, the paper offers a research plan for oral health literacy that proposes some of the questions that we believe must be answered to develop a better understanding of this important determinant of health.

Background

Literacy and other potential contributors to oral health. A broad range of factors, including literacy, is likely to influence oral health. The strategic plan for the National Institute of Den-



Source: Adapted from Institute of Medicine. *Health literacy: A prescription to end confusion: Executive summary*; 2004, p. 5.

tal and Craniofacial Research, for example, highlights the “unique biology of individuals, behavioral lifestyles, the environment, and the organization and financing of healthcare” as key factors (10). Similarly, *Oral Health in America* discusses individual biology and genetics, access to health care, the organization of care, the environment (including physical and socioeconomic aspects), and lifestyle and personal behaviors as determinants that “interact over the life span and determine the health of individuals, population groups, and communities—from neighborhoods to nations” (2).

Defining oral health literacy. To define oral health literacy, we begin with a widely used definition from *Healthy People 2010*, the ten-year plan for improving the nation’s health status. That definition is adapted here to the context of *oral health*: “Oral health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic oral health information and services needed to make appropriate health decisions (8).”

This definition addresses *functional* oral health literacy, encompassing knowledge as well as the ability to use that knowledge in making appropriate decisions related to oral health. The definition also acknowledges that oral health information is communi-

cated in a variety of ways. Sometimes it is conveyed via prose (or continuous text), such as on an informed consent form or in a brochure about dental sealants. Other times it is presented in tables or other graphic displays that contain a combination of prose and numerals, such as on a dosage chart for fluoride drops or tablets, a health history form or in a treatment schedule. Oral health information is also communicated in speech, such as in a conversation between a health care provider and a patient. Therefore, oral health literacy encompasses far more than reading; it also involves writing, numeracy, speaking, and listening (11).

However, this definition does not directly address two sides of the equation that comprises health literacy. Individuals are expected to use print materials and spoken presentations in order to take needed action. One might expect that both written and spoken communications have been shaped with awareness and care. Often, this is not the case. As is noted above, presentations may not be clear, professional jargon or scientific terms may be used in place of common words, needed explanations may not be offered, or faulty assumptions about common knowledge may have shaped the message. The Health and Human Services report on Communicating Health expands the defini-

tion of health literacy to include system-level contributions (12).

A multi-dimensional model. Numerous models have been developed to characterize the interrelationships among macro- or systems-level factors and individual factors such as biology and behavior in determining health (13). Figure 2 offers one model that is particularly useful in thinking about the interplay among oral health literacy, culture and society, the health system, and the education system, and their collective role in determining oral health outcomes and costs. According to the Institute of Medicine (IOM) report from which it is drawn, this health framework "illustrates the potential influence on health literacy as individuals interact with educational systems, health systems, and cultural and social factors, and suggests that these factors may ultimately contribute to health outcomes and costs. . . ." Among these factors is an expanded notion of culture. The model drawn from the IOM report includes, in the definition of culture, an understanding of a special language and culture associated with health professionals and its potential clash with the culture and language of the general public. Research is needed to establish the nature of the causal relationships between and among the various factors portrayed in the framework. (6)

The potential role of literacy. The Institute of Medicine report released in April 2004 estimated that nearly half of the adult population in this country, or as many as 90 million adults, "cannot fully benefit from much that the health and health-care system have to offer" because they have difficulty reading and processing the types of health information that they are likely to encounter in everyday life (6). This estimate is based on data from the 1992 National Adult Literacy Survey (NALS) and subsequent literacy and health analyses, *Literacy and Health in America* (4,14). Limited literacy skills are expected among recent immigrants, many of whom are still learning the English language. In addition, many recent immigrants have limited lit-

eracy skills in their native language. However, a significant proportion of native-born adults have limited literacy skills, most especially elders, people living in poverty, and those with less than a high school diploma or General Education Development (GED) certificate.

The lack of research evidence prevents us from drawing any firm conclusions about the impact of limited literacy skills on oral health outcomes, but preliminary evidence from medical and public health research suggests that it may be quite significant, particularly in combination with other determinants of oral health. Once again, the barrier metaphor is useful. For example, while access to insurance and care are primarily economically based, access might also be related to literacy. Many individuals who are eligible for Medicaid or other entitlement programs fail to enroll. Explanations may include lack of awareness, lack of information about enrollment, or inability to successfully complete the application forms or respond to required follow-up inquiries. A 1995 study conducted in two public hospitals indicated that almost half (46%) of the English-speaking patients did not understand the rights and responsibilities section of a Medicaid application, and 60% did not understand a standard informed consent document (15). At the same time, these materials and others like them have been assessed at reading grade levels that far exceed the average reading abilities of high school graduates. Another recent study of emergency room patients found that three-quarters of those with limited skills did not know if they were eligible for free care (16).

Literacy skills may also have a strong impact on a person's awareness of the importance of oral health and its relation to general health and knowledge of specific health-promoting behaviors. Written materials related to fluoride, sealants, canker sores, dental care, smoking, or oral cancer detection are widely disseminated, but their content is only accessible to those who are able to read well and who are able to understand spe-

cialized words and concepts of dental care that are frequently used but seldom explained.

Although we do not yet know the extent to which limited literacy skills play a role, we do know that scientifically based information about oral health is not reaching those who need it. About one-third of U.S. adults are unaware that the primary purpose of water fluoridation is to prevent dental caries. More than three-quarters do not know that dental sealants prevent tooth decay, and about the same percentage cannot identify any of the numerous signs of oral cancer. These percentages are even higher among adults with low levels of education, racial/ethnic minorities, and disadvantaged groups (2, 17).

If health care providers, researchers, educators and policy makers are serious about eliminating such disparities and improving oral health outcomes for all, as we believe they are, then much more needs to be done to ensure that information about oral health reaches those who need it most. This requires a far more detailed understanding than we currently possess of the role of literacy in attaining and maintaining oral health.

Literacy and Health Findings to Date.

Health researchers and practitioners have long known that health is connected to education and socioeconomic status, but the nature of these connections has not been fully examined. Literacy, a critical component of education, may well serve as a major pathway to health outcomes, and by extension, to oral health outcomes. It is helpful to consider what we now know about relationships between literacy and general health as a starting point for oral health literacy research. This section distills the extensive body of work that has been carried out in this area of inquiry.

Medical and public health studies. A majority of research on health literacy has focused on the readability of health materials. Over 300 studies conducted over the span of several decades indicate a mismatch between the literacy demands of health materials such as messages, booklets,

and forms and the reading skills of the audience for whom they were developed. In fact, most commonly used public health and medical materials (including educational materials, directives, forms, and documents) are written at a level that is too difficult for adults with average skills to use (18-20). Within the past decade, a small number of researchers have begun to measure aspects of patients' literacy skills and compare health outcomes for those with limited skills and those with more advanced skills. This research is providing important new information about the relationship between education and health.

To date, most of the reported health literacy findings in research studies are based on the Rapid Estimate of Adult Literacy in Medicine (REALM), a word recognition test that evaluates participants' ability to read from a list of common medical terms and yields grade-range estimates of reading ability. The test is quick to administer, requiring only a few minutes, making it practical for use in clinical settings. The general REALM instrument has since been adapted to specific diseases, including arthritis and diabetes.

Other researchers have used the Test of Functional Health Literacy in Adults (TOFHLA) to assess patients' skills. The TOFHLA was designed to encompass a broader range of literacy skills than the REALM. The original version of the assessment, which takes 22 minutes to administer, contains a 17-item test of numerical ability and a 50-item test of reading comprehension based on the cloze procedure (in which key words are deleted and must be inserted by the test taker). A shorter version was subsequently developed in response to researchers' needs. An even shorter variation, consisting of a cloze test is now most frequently used.

Overall, the findings of these studies using the REALM or TOFHLA show a relationship between reading skills and health-related outcomes such as knowledge of disease, of medicines, and of regimens; ability to follow a set regimen; and incidence of hospitalization. Specifically, adults

with limited reading skills tend to know less about their disease or their medical regimen, are less likely to engage in preventive services, and may be more limited in their ability to manage their chronic disease. Similar explorations have been undertaken with individuals who have diabetes, asthma, and HIV-AIDS (5).

While there has been little attention to date on the ways in which literacy serves as a pathway or a barrier to oral health, a handful of recent studies have examined dental health knowledge, beliefs, and practices, and communication between dental practitioners and patients (21) Like the health literacy research described earlier, most of the existing work has focused on analyzing the readability of print materials for dental patients (e.g., materials on education and oral cancer) and on patients' ability to read and comprehend the meaning of dental words.

It is important to note that, thus far, health literacy researchers have focused almost exclusively on reading materials and on links between adults' reading skills and health outcomes. Researchers have yet to examine the full array of literacy skills—reading, writing, speaking, listening, and basic mathematics and their relationship to health outcomes. This broader domain still needs to be explored.

The Health Activities Literacy Survey. The 1992 National Adult Literacy Survey (NALS) offers more insight into the possible pathways between literacy and health. It moved beyond a narrow focus on reading skills alone to focus on functional literacy—that is, the ability to use print materials to accomplish tasks. Rather than measure discrete, decontextualized aspects of reading proficiency, it used a range of print materials commonly encountered in everyday life at home, in the community, and at work to assess respondents' ability to perform approximations of authentic tasks. These tasks varied in difficulty and complexity and required the participant to use everyday prose and documents, ranging from newspaper articles and bus

schedules to bank advertisements and prescription labels.

In a recent study using the NALS database, researchers analyzed respondents' performance on the 191 health-related tasks included in the NALS and other related large-scale literacy assessments (14). In doing so, they created a useful taxonomy to classify the different groups of health-related activities that individuals engage in both within and outside of health care contexts:

Health promotion (enhancing and maintaining health). Examples include using information from a food label to interpret nutritional information to decide what products to purchase.

Health protection (safeguarding individuals and communities). Examples include interpreting water quality reports or deciding which position to vote for in a fluoridation referendum.

Disease prevention (taking preventive measures and engaging in early detection). Examples include using a booklet about periodontal disease prevention, interpreting a posting about oral cancer screening tests, or understanding a letter and chart communicating test results.

Health care and maintenance (seeking and forming a partnership with providers). Examples include reading and filling out a health history form, following the dosage instructions on a medicine label, and adhering to follow-up instructions.

Systems navigation (gaining access to needed services and understanding rights). Examples include completing an application for benefits, understanding a statement of rights and responsibilities, or offering informed consent.

Based on this spectrum of tasks, the researchers created a new health activities literacy scale (HALS) linked to the NALS database (14). The resulting analyses provide base line information about the health literacy skills of the U.S. adult population overall and of at-risk populations. In this study, health literacy skills are shown to vary by education, age, access to resources, nativity, and race/ethnicity. Those adults with stronger skills have a high school or GED de-

gree or higher, report using documents at work, report getting information from newspapers or other written materials, and having few restrictions on everyday activities because of health issues. Furthermore adults with access to resources such as a savings account or income from dividends have stronger skills than do adults without such resources. This is true for younger as well as older adults (14). These findings convey the powerful impact of social factors on literacy and on health outcomes, setting the foundation for future examinations of literacy as a mediating factor in oral health disparities. The findings do not, however, differ from the overall NALS findings since the HALS scale is based on a selection of items and tasks from the NALS and other large-scale literacy assessments using the same definition of functional literacy and measurement parameters. Only a new survey, drawing randomly from a full collection of health materials and tasks, could offer a comparison of literacy skills in health contexts. Findings from such an assessment would enable researchers to compare to literacy skills in health contexts alone to literacy skills in other everyday contexts.

The Need for Oral Health Literacy Research

Starting points for inquiry. Findings from health literacy studies to date can inform research initiatives in oral health. At the same time, it is important to point out that the studies described in the previous section have been limited in a few important ways. For example, the instruments used to assess health literacy skills (the short form of the TOFHLA and the REALM) offer approximations of reading skills and do not measure functional literacy (6). Furthermore, existing health literacy assessment instruments have been designed for use in medical settings and need to be adapted for studies in oral health settings.

Consequently, the research undertaken in oral health may build on but ought not be limited to the types of inquiries developed in medicine and

public health. As researchers in oral health shape studies based in oral health contexts, they will benefit from a broader purview, understanding, for example, that individuals obtain oral health information from a variety of places outside of the dental/medical encounter. Accordingly, oral health literacy research will need to tap into health-related actions and decisions that occur in other contexts, such as at home, in the market place, and in the community. Furthermore, no systematic examinations of literacy effects on health communication have been reported. Consequently, researchers may be encouraged to explore oral health information delivered through speech and visuals on television and on the radio that is delivered through verbal and visual modes of communication. These include not only television and radio, but also the critical exchanges that occur between patients and dentists, patients and dental hygienists and patients and other staff members of dental offices and clinics.

Additionally, researchers in oral health might apply a schema for examining oral health literacy that allows them to address the many different purposes embodied in oral health communications (e.g., to raise awareness about the importance of oral health, to spur action, or to provide directions for care and follow-up). Then, researchers might examine whether or not the materials are designed for use so that individuals can more easily accomplish needed tasks. Thus, the concept of functional literacy may offer some interesting opportunities to examine linkages between individuals' understanding of various types of health communications and the kinds of decisions and actions they make based on these understandings. Such studies would shed light on the current status of oral health literacy as well as identify problems and shortcomings in existing communication approaches.

Guiding Questions

To set the stage for a comprehensive oral health literacy agenda, this paper proposes three fundamental

questions that are examples of the types of research we feel are needed: *descriptive studies* that provide the information needed to develop interventions, *correlational studies* that identify the relationships between oral health literacy and oral health outcomes, and *intervention studies* that test the efficacy of improved oral health literacy practices.

Descriptive question: What types of literacy tasks do people need to perform within the context of oral health? While knowledge does not guarantee action, information raises awareness and may well help people make decisions. Individuals with limited literacy skills have fewer resources available to help them gain knowledge of available services, of how to maintain and protect their health, and of how to manage chronic illnesses. Thus, it is important to measure the fit between individuals' literacy skills and the literacy demands being placed on them.

To more readily characterize the demand side of this equation, we need a comprehensive analysis of oral health materials and an understanding of how people are expected to use the materials to accomplish tasks commonly encountered in everyday life. This analysis includes written as well as spoken materials, ranging from newspaper and magazine articles to public service announcements, educational materials, health history forms, Medicaid forms, informed consent documents, and more. The selected materials should represent a variety of contexts and contents. The schema developed for the analysis of literacy and health in Literacy and Health in America (14), as described earlier, will be useful for such an analysis. Included would be materials on *health promotion* (enhancing and maintaining health), *health protection* (safeguarding individuals and communities), *disease prevention* (taking preventive measures and engaging in early detection), *health care and maintenance* (seeking and forming a partnership with providers), and *systems navigation* (gaining access to needed services and understanding rights). Such materials could focus on particular diseases

(e.g., dental caries, periodontal disease, oral cancer) or on oral health in general. Both types of analyses are needed.

The oral health materials that are collected for analysis must also represent a variety of formats. Some of the oral health materials provided for people to read and use are written in prose (continuous texts), while others are documents, forms, charts, maps, and graphs (non-continuous texts). The two types of texts are organized differently, and so readers have to employ different strategies to read, extract, and use information from them. We must examine these materials in light of what is known about clear texts and about U.S. adults' literacy skills.

However, it will not suffice to simply analyze the oral health materials by themselves; researchers must also focus on the types of tasks that individuals typically need to perform using them. Previous research has shown that numerous variables influence the complexity and hence the difficulty of literacy tasks, and such analyses are needed within the context of oral health literacy as well.

Once this body of oral health materials and tasks is assembled, it must be analyzed by experts to produce an index of oral health literacy demands that reflects the range of demands for each item, carefully calibrated and assessed by complexity and task. This effort would produce a catalogue of oral health demands that are placed on individuals in everyday life.

Correlational question: Is literacy a good predictor of oral health outcomes, above and beyond level of education? Although socioeconomic status—defined in terms of education, income, and occupation—is known to be an important predictor of health, most of the studies performed to date have not examined education in and of itself and disaggregated the separate influence of its components (22). This research focus addresses the need to develop models that explain existing disparities in oral health outcomes among various groups.

As depicted in the framework (Figure 2), literacy is hypothesized to be

one of many factors that influence oral health. Therefore, the first step toward discerning the role of literacy in a multidimensional model of oral health is to determine if literacy skills explain health disparities, or if disparities still exist among those with equivalent levels of literacy. Once the relationship between literacy and oral health (independent of education and other socioeconomic status markers) is determined, we can begin to incorporate other determinants in our explanatory models and see how these determinants interact with literacy. According to the model, such determinants may include economics, cultural and other social factors, education, and various characteristics of the health system.

Intervention question: How can we improve the practice of communicating oral health information (e.g., adapting print materials, including non-print alternatives, or training providers in appropriate communication skills)? While efforts to strengthen literacy proficiencies in the population are critically important, focused attention is also needed on mechanisms for improving how health information is communicated. This research question extends the focus on improving skills to ways of moderating literacy demands.

Health communication, of which health literacy is a part, has received much attention in recent years. Scholars and practitioners recognize that health communications must be clear and understandable to all and that they must be sensitive to recipients' cultural and social backgrounds (6). Attention to these issues may well serve to bridge the current gap between research findings and public knowledge (23).

According to the NIDCR's strategic plan: "ensuring that target audiences become informed, make appropriate decisions about their health, and adopt behaviors that will improve their health, requires *further advancement of our tools to communicate with audiences effectively*. We also must enhance the public's *access to and use of the most current science-based health information*" (emphases added)(10).

Concomitantly, it is important to conduct research on the role and needs of dental health providers as they convey health information and gather important data from patients. To begin this work, we need to examine the communication skills taught to dental and dental hygiene students and add readings and discussions about health literacy. In addition, we need to determine what knowledge and skills providers need to more adequately address literacy issues in clinical and public health practice. Finally, research studies focused on best practices are needed. The American Medical Association recommends using the 'teach back' method—that is, asking a patient to explain what the physician has said regarding the patient's condition. Yet, little research has been conducted on this method in general health and none has been conducted in dentistry.

Previous research has shown the effectiveness of some communication strategies including: giving meaningful examples, demonstrating procedures, asking patients to demonstrate a given procedure, asking individuals to restate instructions in their own words, repeating information several times, presenting the most important information first and last, and involving family members or other caregivers (24). Such intervention studies are needed within the context of oral health. Effectiveness studies would help guide practitioners in their attempts to communicate well with a variety of population groups—particularly the elderly, recent immigrants with limited English proficiency, and those in different racial/ethnic groups.

Studies are also needed to compare the results of presenting the same information to similar groups in a variety of different ways. These studies should reflect the full spectrum of health communication—not just printed materials designed for the oral health care setting, but also verbal instructions as well as discussions in mass media, drawn from a wide range of everyday contexts.

The initial inquiries described here would inform practice and policy.

They would support public health program designers, oral health care providers, as well as community-based partners, such as adult educators, to improve oral health communication efforts and to increase dissemination among those with limited literacy skills.

Instrumentation

We have long known that educational achievement is linked to health outcomes, dramatically so in the case of chronic diseases (25). Previous studies in the newly emergent field of health literacy have shown that reading skills are related to health knowledge and outcomes. Research studies, currently underway, are examining other components of education in efforts to elucidate the pathways from education to health. Such work must be expanded to include outcome measures in oral health as well. Therefore, an important part of the research effort proposed here is the development of instruments that will allow researchers to assess oral health literacy skills. A thorough analysis of existing materials combined with a thoughtful analysis of tasks would yield a great deal of insight into demands for the redesign of oral health messages and materials and, most importantly, also serve to shed light on the links between education and oral health.

Short assessment instruments designed to measure the oral health literacy of individuals are likely to be useful. These instruments would make it possible for researchers to study the connections between individuals' literacy skills and outcomes such as awareness of the importance of oral health to general health, knowledge of specific oral health behaviors, oral hygiene, disease management, and participation in screening programs.

One possible pathway is the development of an instrument modeled after some of the tools that offer approximations of reading skills, such as the REALM, but modified to be suitable for oral health contexts. Assessments designed specifically for the oral health context would be an im-

provement over these earlier instruments in terms of face validity. However, they would need to be tested against other instruments to determine whether they are equally predictive. The use of such instruments would begin to inform researchers about the extent to which oral health literacy is linked to a variety of outcomes.

The call to action of the IOM's report *Health Literacy: A Prescription to End Confusion*, highlights the importance of tapping into a broad array of literacy skills that go beyond reading skills alone and include speaking and listening skills, as well as quantitative abilities. All of these are part of oral health literacy and they must also be part of the assessment repertoire.

Conclusions

Over the past several decades, researchers' understanding of the causes and treatment of oral diseases has grown exponentially. Yet the incidence of preventable oral diseases remains high, and there are profound and consequential health disparities within our population. The most advantaged people in the United States enjoy the best oral health status in the world, while the most disadvantaged have health needs and conditions that are equivalent to those in the poorest nations.

As *Oral Health in America* makes clear, improving the nation's oral health status will require greater public awareness of the importance of oral health and its link to general health, as well as greater understanding of the actions that can improve health and prevent disease. Efforts to build awareness and knowledge must be informed by the most current approaches and materials design and development findings. We can no longer tolerate the mismatch between materials developed by professionals and the skills of the reading public. Insights provided by national and international assessments of adult literacy skills must shape communication and dissemination efforts.

Health provider training and practice must also change. Health providers must become far more knowledge-

able about literacy, and more sensitive to social and cultural factors that influence health. More specifically, the communication component of dental and dental hygiene education must be strengthened so that providers learn to use plain-language approaches and not to rely on print materials alone for instructions and follow up.

Furthermore, the question of whether providers should be compensated for the time they spend educating patients about oral health must be addressed. At present, no third-party reimbursement for patient education is available. Based on the old "time is money" adage, even well-meaning providers who want to incorporate more effective ways of educating and communicating with their patients literally may not be able to afford to do so. This issue must also be examined and addressed.

Because communication is a two-way endeavor, efforts to educate providers about literacy must be joined by efforts to improve oral health literacy skills in the population as a whole. Research findings indicate that education is linked to health outcomes and literacy is a key component of education. When half of the US adult population is found to have limited literacy skills, a call to improve skills among children and adults is warranted.

The K-12 and adult education systems could play a key role in this undertaking. A handful of programs are now underway to improve oral health awareness and literacy among school-aged children. For example, the Academy of General Dentistry is developing national oral health literacy standards and developing an oral health literacy curriculum that they hope to enact in K-12 schools across the United States (26). Such efforts to educate children about oral health may hold promise for reaching parents as well, if the materials sent home are appropriate for adults and closely match their vocabulary and reading skills.

Adult basic education programs and English as Second Language programs may also provide an important

avenue for strengthening oral health literacy skills. These programs serve approximately 3 million adults in the United States, and therefore represent a tremendous opportunity for interventions around oral health literacy. Other institutions that serve adult learners—such as community colleges (developmental education programs), public and medical libraries, professional and community groups—can also offer health literacy programs that target skill improvement for low-literacy and limited-English-proficient individuals. In addition to such programs, the field urgently needs books and materials to teach adult learners how to read and at the same time increasing their understanding about oral health materials. Appropriate materials are scarce.

Improving oral health literacy will require intensive collaborative efforts among health providers, researchers, educators, policymakers, public officials, the commercial sector, and, of course, the public. Ultimately, the goal of these multifaceted initiatives is the reduction of literacy barriers to oral health in order to ensure that health communications are accessible to all. At present, the information and insights from new oral health research and the development of new technologies for prevention and treatment are frequently neither adopted nor used by those who need them most. We must encourage efforts to 'design for dissemination'. Efforts to understand and improve oral health literacy may serve as an important means of helping to close the gap between knowledge and action.

Acknowledgement

The authors thank Lynn B. Jenkins for her pivotal work as scribe during the workshop.

References

- Throughout this paper, we use the term "oral health" to refer to the health of all aspects of the mouth and related craniofacial structures—including the teeth, gums and supporting tissues, hard and soft palate, mucosal lining of the mouth and throat, tongue, lips, salivary glands, chewing muscles, and upper and lower jaws. Thus, oral health encompasses more than just healthy teeth.
- US Department of Health and Human Services. Oral health in America: A report of the surgeon general. Executive summary. Rockville, MD: USDHHS, National Institute of Dental and Craniofacial Research, National Institutes of Health, 2000.
- Horowitz AM. The public's oral health: The gaps between what we know and what we do. *Adv Den Science* 1995;9:91.
- Kirsch I, Jungeblut A, Jenkins L, Kolstad A. Adult literacy in America. Washington, DC: US Department of Education, 1993.
- Berkman ND, DeWalt DA, Pignone MP, Sheridan SL, Lohr KN, Lux L, Sutton SF, Swinson T, Bonito AJ. Literacy and Health Outcomes. Evidence Report/Technology Assessment No. 87 (prepared by RTI International-University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016). AHRQ Publication No. 04-E007-2. Rockville, MD: Agency for Healthcare Research and Quality. January 2004.
- Institute of Medicine. Health literacy: A prescription to end confusion. Washington, DC: National Academies Press, 2004.
- Parikh NS, Parker RM, Nurss JR, Baker DW, Williams MV. Shame and health literacy: The unspoken connection. *Patient Educ Couns* 1996;27.
- US Department of Health and Human Services. Healthy people 2010. 2nd ed., Vol. II: Oral health. Washington, DC: US Government Printing Office, 2000.
- US Department of Health and Human Services. A national call to action to promote oral health. Rockville, MD: US Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention and the National Institutes of Health, National Institute of Dental and Craniofacial Research. NIH Publication No. 03-5303, 2003.
- National Institute of Dental and Craniofacial Research. Strategic initiatives: Health disparities. In: Strategic plan. Bethesda, MD: NIDCR. www.nidr.nih.gov/about/strat-plan/strategic.asp. Accessed 06 July 2004.
- To avoid confusion in this paper, we use the terms "speaking" and "verbal" rather than "oral" to denote ways of communicating health information in conversation; we reserve use of the term "oral" to refer to the teeth and mouth, as in "oral health."
- Rudd R. Objective 11-2 Improvement of Health Literacy. In: U.S. Department of Health and Human Services. Communicating Health: Priorities and Strategies for Progress. Pp35-60. Washington, DC, July 2003.
- Institute of Medicine. The future of the public's health in the 21st century. Washington, DC: National Academies Press, 2002:51-3 and Appendix A.
- Rudd RE, Kirsch I, Yamamoto K. Literacy and health in America. Princeton, NJ: Educational Testing Service, 2004.
- Williams MV, Parker RM, Baker DW, Parikh NS, Pitkin K, Coates WC, Nurss JR. Inadequate functional health literacy among patients at two public hospitals. *JAMA* 1995 Dec 6; 274(21):1677-82.
- Baker DW, Parker RM, Williams MV, Clark WS, Nurss J. The relationship of patient reading ability to self-reported health and use of health services. *Am J Public Health* 1997; 87.
- National Institute of Dental and Craniofacial Research. Facing the challenges. In: Strategic plan. Bethesda, MD: NIDCR. www.nidr.nih.gov/about/strat-plan/strategic.asp. Accessed 06 July 2004.
- Rudd RE, Moeykens BA, Colton TC. Health and literacy: A review of medical and public health literature. In: Comings JP, Garner B, & Smith C, editors. The annual review of adult learning and literacy. San Francisco: Jossey-Bass, 1999:158-99.
- Rudd RE, Colton T, Schacht R. An overview of medical and public health literature addressing literacy issues: an annotated bibliography. National Center for the Study of Adult Literacy and Learning Report #14. Harvard School of Public Health: Health literacy web site, 2000. www.hsph.harvard.edu/healthliteracy/litreview.pdf. Accessed 06 July 2004.
- Krause EMS. An overview of medical and public health literature addressing literacy and informed consent for research participation: an annotated bibliography of articles published between January 2000 and May 2001. Harvard School of Public Health: Health literacy web site, 2001. www.hsph.harvard.edu/healthliteracy/literature3.html. Accessed 06 July 2004.
- Emmer C. Oral health literacy annotated bibliography. Boston: Harvard School of Public Health. www.hsph.harvard.edu/healthliteracy/literature/lit_oral.html. Accessed 06 July 2004.
- Institute of Medicine. Understanding population health and its determinants. The future of the public's health in the 21st century. Washington, DC: National Academies Press. 2003:57.
- Institute of Medicine. Speaking of health: assessing health communication strategies for diverse populations. Washington DC: The National Academies Press, 2002.
- Doak C, Doak L, Root J. Teaching patients with low literacy skills. 2nd ed. Philadelphia: J.B. Lippincott Company, 1996.
- Pamuk E, Makuc D, Heck K, Reuben C, Lochner K. Socioeconomic Status and Health Chartbook. Health, United States, 1998. Hyattsville, MD: National Center for Health Statistics, 1998.
- Academy of General Dentistry Foundation. www.agd.org/foundation/grants.htm. Accessed 06 July 2004.