

Health Literacy Grantee Meeting
December 15, 2008
Gaylord National Resort and Conference Center
National Harbor, Maryland

Welcome and Overview

Dr. Lynne Haverkos, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health

Dr. Lynne Haverkos welcomed the group and thanked the organizing committee for their efforts in putting together this meeting. Following the April 2004 Institute of Medicine report, “Health Literacy: A Prescription to End Confusion,” the National Institutes of Health (NIH) issued a series of Program Announcement with Review (PAR) on “Understanding and Promoting Health Literacy.” Led by the NIH’s Office of Behavioral and Social Sciences Research (OBSSR), the initiative was supported by the Agency for Healthcare Research and Quality (AHRQ) and various NIH Institutes and Centers. The goal of the PAR is to encourage empirical research on health literacy concepts, theory, and interventions as they relate to public health priorities identified in Healthy People 2010. To date, 50 individual awards have been made in response to this solicitation, and today’s meeting invites discussion of lessons learned and to be learned in health literacy research, as informed by this growing research base.

Panel Discussion: Measurement and Methodology

Moderator: Dr. Carmen Moten, National Institute of Mental Health

How is health information best shared? What methods will best answer the question?

Dr. Stephen Porter, Children’s Hospital, Boston

High-level goals of any biomedical and behavioral research methodologies include scientific designs that highlight causal pathways, identify key relationships, and delineate effect size and direction of influence; recruitment strategies that successfully enroll and retain subjects whose participation is essential to answer the questions; and monitoring of protocols that allow for targeted adjustment to design and recruitment strategies as needed. However, real-world challenges complicate meeting these goals.

Dr. Porter described his own experience investigating health literacy and information management in Attention-Deficit/Hyperactivity Disorder (ADHD). Health literacy is relevant to all aspects of the pathway from data to action, and he has used structured communication to recruit and engage parents of children with ADHD without significant co-morbidities. This two-phase project involves a user-centered design process to refine computer-based method of data input by parents of children with ADHD, followed by a

randomized trial of paper-based and computer-based data entry tasks with health literacy as the primary variable of interest.

Recruitment challenges (largely due to difficulties in finding low-literate parents for the cohort) led to a re-designed trial that maximizes data from each subject. This approach enabled study of order effect for data entry tasks with regard to what answers are given as well as study of how the structured electronic environment influences parents' written communication of current medications.

Lessons Learned:

- Interactions between health literacy and technology pose both a challenge and an opportunity.
- Technologies are at the same time communication tools and independent constructs for assessing health literacy.
- System-level interventional research on structured communication may help to untangle these variables and inform future efforts.

Measuring Health Literacy Using a Skills-Based Approach

Dr. Lauren McCormack, RTI International

What is health literacy? Many definitions have been proposed that address several basic concepts: i) the ability to perform basic reading and numerical tasks; ii) the ability to function in a health care environment; iii) attributes that predict one's ability to gain access to, understand and use information in ways that promote health; and iv) a link between knowledge and practice. Dr. McCormack cited her own working definition of health literacy:

“The degree to which individuals have the capacity to obtain, process, understand, and communicate about basic health information and services needed to make informed health decisions, using materials in the health and health care environment.”

Dr. McCormack's project aims to measure people's ability to use different types of health information to make informed health decisions throughout life, and in periods of health and illness. Issues range from skills for disease prevention to treatment and self-management. In this study, a criterion-guided, hierarchical approach identified in a stepwise fashion a skill/task, then a stimulus, then a mode of administration. Sample instruments included health calculators, questionnaires, surveys, and news media content. A key limitation of these approaches is that most center on reading ability in some way.

Lessons Learned:

- Is there a need to distinguish literacy and health literacy?
- Finding good, “real-world” stimuli is difficult.

- Achieving the right range of difficulty is more of an art than a science.

Issues in Methods and Measurement: Health Numeracy

Dr. Marilyn Schapira, Medical College of Wisconsin

Dr. Schapira defined health numeracy as:

“The ability to understand medical information presented with numbers, tables and graphs, probability, and statistics, and to use that information to communicate with your health care provider, take care of your health, and participate in medical decisions.”

She then described her own framework for investigating health numeracy and presented justification for developing the Numeracy Understanding in Medicine Instrument (NUMi). Existing health numeracy measures are either composite or integrated assessments and include: the National Adult Literacy Survey¹, the Test of Functional Health Literacy in Adults (TOFHLA²) numeracy component, and The Newest Vital Sign³. A range of other health literacy instruments are general, subjective, or disease-based. All are somewhat limited in that they i) invoke limited input from the patient perspective; ii) are not developed to target the study of numeracy in different race/ethnic and cultural groups; and iii) have a high respondent burden.

The NUMi aims to address some of these limitations by i) establishing the content validity of a health numeracy construct from the patient perspective and a cross-cultural point of view; ii) developing a method to assess a full spectrum of skills; and iii) using psychometric methods.

Lessons Learned:

- Health numeracy reflects skills in using, interpreting, and applying quantitative information in the health-care context.
- A patient’s perspective and cross-cultural research can help to define and validate a health numeracy construct.
- Tailored approaches are best for patient communication and decision making.
- Future efforts should assess interventions designed to improve numeracy.

¹ Educational Testing Service, Princeton, NJ. National Center for Education Statistics (ED), Washington, DC . Full document not available: Document summary accessed December 16, 2008 at http://www.eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/20/8b/93.pdf

² Parker RM, Baker DW, Williams MV, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med.* 1995;10:537-41.

³ Weiss BD, Mays MZ, Martz W, Castro KM, DeWalt DA, Pignone MP, Mockbee J, Hale FA. Quick assessment of literacy in primary care: the newest vital sign. *Ann Fam Med.* 2005;3:514-22.

Discussion Themes

Recruitment

Health literacy study recruitment is hampered by the homogeneity of high-literate subjects as well as difficult access to “non-joiner” populations. Building relationships through partnerships with low-literate communities can enhance public trust required for effective recruitment of low-literate subjects.

Definitions

Different definitions of health literacy and confounding variables (prior knowledge, communications preferences among people) may complicate health literacy methods development.

Measurement

The use of categories and ranges of measurement may enable more sophisticated analyses of numeracy and uncover subtle differences among individuals and populations.

Breakout Session: Measurement (definitions, tools, and processes)

CO-FACILITATORS:

Elizabeth A. Hahn, MA, *Feinberg School of Medicine, Northwestern University*

Robert M. Hauser, PhD, *University of Wisconsin-Madison*

PARTICIPANTS:

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Among the issues addressed during the discussion were: 1) how can health literacy be defined; what should be included in the scope (health education, health communication, cultural competency, *etc.*); and how can health literacy be characterized as more interdisciplinary; 2) what are the current measures of health literacy, do they adequately capture health literacy of the population, and can they measure changes in health literacy over time; 3) what new measures are needed (*i.e.*, phone-based instrument) and what innovation do they offer; and 4) consider "consistency" issues in the measurement and reporting of health literacy (vision, cognition, spoken *vs.* written language, and continuous *vs.* categorical scales).

Health literacy, as defined by the National Academies' Institute of Medicine (IOM), is the "degree by which individuals have the capacity to obtain, process, and understand basic health information".

For individual projects, investigators tend to scale back the classic definition of health literacy, and split up the components from the IOM definition into capacity of obtaining, capacity of processing, and capacity of understanding basic health information.

Note: A recent National Academies of Science (NAS) report on health literacy can be found, as a searchable pdf, at www.nap.edu.

Below are highlighted the main discussion points focusing on current definitions of health literacy, based on individual projects:

Example: Researchers at Vanderbilt University are developing a health literacy instrument for pediatrics, based on measuring parental health literacy as opposed to caring for young children: Pediatric Health Activity Test (PHAT). Health literacy in the context of the PHAT project is defined as "the ability to read, understand, and apply health information to the care of a child."

- incorporating more numeracy tests to get to some of the numeracy skills
- managing child health activity in early childhood

- measuring child health literacy throughout development, from early childhood onwards
- measuring caregivers' health literacy

Example: Researchers at University of Washington are working on putting the "function" into functional health literacy

- track parents' health literacy over time with a series of functional measures; this is not a reading task, but instead home visitors are observing and are rating the healthcare behaviors and tasks performed by parents (tasks of parenthood)

Note: Behavior as related to literacy is problematic to work with, because there are motivational factors that influence behavior, not only the health literacy that an individual possesses. The science of behavioral change should not be ignored: there is a loss of precision when incorporating all these behavioral models under the umbrella of health literacy.

Example: In linguistics –not health literacy but literacy– researchers look at competence and performance, and neither is very precise. One of the meeting participants is currently working with the City of New York, asking doctors to assess their own health literacy around a range of issues.

- it is very difficult to measure someone's literacy, in any empirical way, if it is de-contextualized, taken out of real-life situations

Example: There is a need to assess the oral demand/burden that is presented to patients. Rather than determining how precisely can every aspect of oral literacy be measured, researchers could come up with a paradigm shift: from what is it about an individual that is at deficit to what is it about the context in which they are engaging that presents too much of a burden. Both sides of the equation need to be considered, not just what deficits individual patients might have, but what demands and burdens are being introduced by the medical community.

- shift from assessing a person's health literacy to assessing the doctor-patient dialogue
- the burden of oral medical dialogue or print materials is going to overshoot the capacity of the population; for instance, most informed consents overshoot what people can read
- as a short-term goal, the purpose will be not to improve everybody's health literacy, but to reduce the burden in many different domains, like the print domain, or in the medical dialogue
- need to reduce the burden in community access to medical services, community and environmental health services
- medical malpractice has similarities with public health malpractice in increasing the burden for most people
- in terms of provider-patient interaction, there is a need to assess the extent to which threat is taken into account, in efforts to deal with the health literacy burden
- threat is a major feature in medical interactions; when someone is diagnosed with a terminal disease, there is a need for a "note taker" to accompany the patient; the

patient can be relatively health illiterate in that situation and someone else needs to make a record of the dialogue between the doctor and the patient

Note: The notion that 50% of the US population is health illiterate is an artifact of the particular technology of scaling used to draw the threshold. The NAS was asked to help develop health literacy standards (search "measuring literacy" on their website to obtain the pdf of their report). Everybody has a different definition of health literacy: capacity, function, observer rating, reading ability, navigation, communication, knowledge. Health literacy is a big, broad, overarching concept, and there is a need to put all of our tools and measures together, a need to agree on terminology.

Meeting participants have briefly presented new, innovative tools currently being tested as measures of health literacy. The main discussion points are highlighted below:

Example: Researchers are measuring peoples' reading-related ability to understand health-related text, in either English or Spanish, with the use of web-based testing. This tool is still in the process of data collection and testing.

Example: Researchers at University of Illinois are measuring health literacy in immigrant women, with respect to ovarian and cervical cancer. The investigators measured attitudes, beliefs, and knowledge and issues related to the interaction between healthcare providers and patients.

- the patients' ability to communicate with their doctor was critical
- having a different interpreter at each visit does not help in the interaction between the immigrant patient and the doctor; women need to develop a certain degree of trust in their interpreter and would voluntarily withhold information due to a lack of trust
- barriers in communication occurred even when women had family members as interpreters
- cultural issues: Philippine women would refuse to pronounce the word "cancer" because by doing so they believe they would certainly bring it into their lives

Example: Researchers at University of Pennsylvania are developing a health literacy tool designed for facilitating the provider-patient interaction regarding asthma medication use.

- immediate feedback: in the context of providing care, the provider targets the burden/demand on the patient
- not an abstract measure of general health literacy, but a real way of measuring immediately the patients' understanding in using an inhaler - very specific to the task at hand
- very efficient tool, because the provider finds out immediately the burden or demand on the patient (for example, number of pills/day)

Example: Researchers at the University of New Mexico are developing two different kinds of health literacy instruments.

- tool designed to assess the comprehensibility of printed materials, developed in the context of HPV and cervical cancer prevention; the tool, based on the Suitability of

Assessment Materials (SAM) and adding comprehensibility (CAM), is now being adapted for oral health literacy

- tool designed to assess competency (functions), developed to look at HPV and cervical cancer health literacy. The researchers included knowledge, attitudes (self-efficacy around communicating with partners or providers; the notion of prevention and its importance) and oral communications (actual conversations regarding the Pap test and interpretation of results, encountered in the medical environment, were recorded and then played by actors).

Example: health literacy measurements in other countries

- new health literacy measurements are influenced by and influencing how other people are testing for it in countries like Singapore, Korea, Japan, Israel, Australia, etc.

Example: Consumer Assessment of Healthcare Providers and Systems (CAHSP), a set of surveys looking at patients' experience of healthcare in different contexts ; there are approx. 40 items that are tested on the field and used to inform the clinicians.

- need to look at the characteristics of the system that are deficient in terms of enabling people to understand healthcare information, and try to address them

Example: Researchers from University of Arizona have a multi-language, multi-instrument project with Vietnamese, Puerto-Ricans, Latin Americans.

- limited confidence in what is actually being measured using different scales in all these different languages: is this culture, is this cognition?
- limitation in abstract thinking
- difficulties with filling in a form do not necessarily reflect low health literacy

Example: Researchers at the University of South Florida are assessing health literacy in the context of mental health

- research with Mexican-Americans, Cuban-Americans, Korean-Americans on how people from mixed backgrounds perceive depression shows significant differences (*e.g.*, Mexican-Americans diagnosed with depression differ on 80% of items from Caucasians)
- health literacy is dependent on people's reasoning abilities, related to cultural competence, but goes beyond
- the language used and the ways the questions are being asked are relevant when assessing health literacy
- health "culturation" as a possible complement or precursor to health literacy

Summary and Conclusions

An individual's capacity, *i.e.*, vocabulary, conceptual knowledge of health issues, reading fluency, is affecting the ability to interact with the healthcare provider. In addition, culture is a strong factor, as there are misconceptions regarding health issues that are part of some cultures. Knowledge influences health literacy, as various abstract concepts are required from a health literate person (*e.g.*, the normal range for blood sugars is not

known, in many cases). Cognitive testing can be useful, such as IQ, or visual puzzles as tests of intelligence for young patients, but all these skills are contextual. There needs to be taken into account the fact that there are individuals with low knowledge *vs.* individuals with low conceptual knowledge, but high reading fluency; as health literacy is a dynamic process, the latter can improve their health literacy significantly, as need arises.

Issue/warning: in the 1960's and 1970's, researchers have made the mistake of looking at African-American English and equating it to poor cognition, ignorance, and low IQ. There is a need to prevent the same thing from happening now, when similarly, low literacy (and health literacy) is influencing cognition and eventually, is influencing people's perceptions.

Some of the health literacy dimensions range from abstract reasoning ability –as a foundation for literacy–to the kinds of general concepts of health literacy that are embodied in the Tests of Functional Health Literacy in Adults (TOFHLA) or CAHSP, as well as to very specific kinds of literacy, pertaining to specific diseases. The health literacy field ought to develop in terms of sheer understanding of what the hierarchy is with respect to competency and variety of domains; all of it is cross-cut by issues of culture, language, and specific social situations.

Breakout Session: Methodology (recruitment, retention, study design, and barriers)

Co-Facilitators

Vish Viswanath, PhD, *Harvard University*

Douglas M. Brugge, PhD, MS, *Tufts University*

Questions

The co-facilitators presented the following questions:

1. What designs do we want to commonly use to collect data and study health literacy? Would context be a part of the design issue?
2. How do we recruit people for studies, and what do we do with issues of retention, particularly with prospective designs?
3. Regarding units of observation and analysis, how do we define and draw boundaries? Do we measure the individual or the network? What would be the methodological challenges of talking about health literacy in the community context?
4. What is the conceptual definition of health literacy?

Discussion

Designs and the role of context

- We cannot use conventional models with small populations.
- Collecting narratives to understand the mental model of the audience you intend to reach will aid in developing effective health messages for use in decisionmaking. It is more labor intensive to make the message relevant to the audience, but it is also more effective.
- To make the population more health literate, start with general, more global kinds of interventions vs. disease-specific interventions. For example, improve skill sets for finding the information people need. If patients know where to find information, they can obtain and use it when they need it.
- Some foreign languages are phonetic and some are character based. This adds complexity to proposals for working with special populations. We need to work together to help peer reviewers understand these difficult conceptual issues as applied to minority populations.

- The issue of language is very important, particularly regarding immigrant populations. Much of the information available in the health care system (e.g., for symptom management issues) is not available in languages other than English. Even in English, much is written at higher reading levels than patients can access. Linguistic translation is not enough; we have to take into consideration the reading level in Spanish, for example.
- The skill of interpreters makes a big difference. For example, sometimes the interpreter is a child, and that also adds complexity.
- It would be helpful to be able to relate the health literacy pieces in a study to the interpersonal and contextual pieces, and particularly to the strengths that emerge in the encounter that may not be measured, or the strengths that families or practitioners bring that may become invisible in the encounter.
- Whether in the home or the hair salon, our methodology may translate into mixed methods, starting with qualitative inquiry to find out where people are making health care decisions and then proceeding with a randomized controlled trial that is quantitative.
- Much of health care occurs in the home (e.g., symptom management for uninsured men who are treated with hormone therapy after surgery/radiation therapy for prostate cancer). When they come to our health care system, they bring with them their own health beliefs and conceptions of how to deal with health care problems. This creates an intersection of two different and often disparate health care systems (U.S. vs. native country); communities and culture add another layer of complexity.

Recruitment and retention

- When you have small population groups, how do you recruit and retain so you can generalize your results? It is very difficult to use a conventional statistical model when you have a sample that is not probability based.
- We have to make sacrifices in study design to reach the populations we want to study. It is hard to find people who are willing to identify themselves as low literate. We have to enter into community partnerships to find these people, and it takes a long time to get the numbers needed to do small studies.

Units of observation and analysis

- It is very difficult to measure health literacy across languages. English language skills and primary language skills vary; spoken vs. written language varies considerably. Another variable is how the patient receives health care information – through an English language provider or interpreter, for example.

- No measures of literacy can be used across more than two languages.
- Do we know enough to be able to characterize what we are trying to measure? Can we do studies that identify causality if we have not identified variables?
- It is important to define the main health domains (such as making doctor appointments and filling prescriptions) for all patients, especially special populations, to ensure we know what all patients need to know.
- NIH wants good basic research that will lead to better health outcomes. There has been and should be a shift from a patient deficit model to a health system deficit model. What can we measure within the health system as an indication of quality or safety, and how does that connect with health literacy?

Definition of health literacy

- The definition of health literacy should take into account that language, especially English language skills, and issues about interpersonal relationships with providers may impact the efficacy of treatment and thus are relevant to what we measure and how we go about it.
- We still do not have empirical evidence to define health literacy.
- We need a taxonomy to pull the dimensions together and get a standardized language. It is the only way the field can evolve in a quantitative fashion. No one part is more important than the others.
- Health literacy is an important component of health communication but not a distinct piece. We need to remember that people act irrationally and use information based on heuristics, belief systems, etc.

Participants were asked to write down and submit to NIH two issues where there are significant gaps that NIH should address.

Breakout Session: Quantitative Literacy (numeracy)

Co-Facilitators:

Dr. Russell Rothman, Vanderbilt University Medical Center; Dr. Deena Chisolm, Ohio State University

Discussion Themes

How should numeracy be defined, and should it be measured separately from literacy?

Multiple definitions of numeracy are necessary for designing research studies and in developing interventions. The science and science policy landscape covers vast ground regarding numeracy. For example, current federal efforts to address numeracy gaps call for population-based study and approaches (*e.g.*, analyzing public views of vaccine safety); whereas many investigator-initiated research examines numeracy as it relates to individual medical decision making (*e.g.*, choosing among cancer treatments). As a community, health literacy researchers should appreciate and consider the variety in scope that is currently employed to understand and improve health numeracy.

What methods should be used to measure numeracy?

Although an individual's numeracy develops from a range of innate and learned factors, it is in many ways a cultural convention. Numeracy is a measure of education, is influenced significantly by life course, and is intertwined with both general and scientific literacy. More research on what impacts numeracy throughout life may inform the development of ways to improve it.

How should we design interventions to improve numeracy?

Because numeracy is context-dependent, interventions may be best tailored to individual needs. For example, efforts to enhance numeracy can be developed in a disease-specific manner (*e.g.*, for cancer prevention, diabetes treatment, or obesity management). It may also be worthwhile in a general sense to aim for a "baseline" numeracy level when designing interventions, since this approach has been successful in other realms of literacy, such as reading. However, numeracy is multidimensional, involving not only the way patients' receive numerically based information but also the manner in which health care providers deliver it. Better systems-level communications training for health care providers may enhance the ability for low-literate populations to understand mathematical concepts about health and disease.

Brown Bag Lunch for Early-Stage Investigators

Moderator: Dr. Robert Logan, National Library of Medicine, National Institutes of Health

An Evidence Form Literacy Strategy: Using HPV Vaccine Narratives to Reach Women Aged 18-26

Suellen Hopper, The Pennsylvania State University

This project employed a narrative communication model for promoting vaccination against human papillomavirus (HPV). The approach considers issues unique to HPV: i) the value of communication's role in translating a preventive vaccine into a widely adopted public health measure; ii) limited health care provider guidelines for the vaccine's use; and iii) the potential for extensive and cost-effective dissemination through university health centers. The tri-phase study involved interviews with college-age women, focus groups to evaluate themes and test messages, and a randomized, clinical study to assess outcomes (HPV vaccination). Mental models that informed development of the video narratives spanned a range of factors including relationship status; vaccine cost, availability, protective value, and safety; and parental/provider normative beliefs.

Is Maternal Health Literacy Associated with Participation in Child Social Welfare Programs?

Dr. Susmita Pati, The Children's Hospital of Pennsylvania

Little is known about the role of parental health literacy in under-enrollment in child social welfare programs. This study was a 3-year prospective longitudinal cohort study of 626 Medicaid-eligible mothers and healthy infants, recruited at birth. The project aimed to determine the relationship between low literacy (as measured by the S-TOFHLA) and participation in social welfare programs including Temporary Assistance to Needy Families (TANF), the Women, Infant, Child program (WIC), food stamps, public housing, and subsidized child care. The study concluded that mothers with adequate or marginal health literacy were more likely to receive TANF than mothers with inadequate literacy. In addition, few Medicaid-eligible families receive public housing or child care. These data suggest that maternal education and health literacy are strongly, but not perfectly, correlated.

Numeracy and Diabetes Self-Efficacy Mediate the Effects of Race on Glycemic Control

Dr. Chandra Osborn, Vanderbilt University Medical Center

Limited literacy and low numeracy have been associated with diabetic patients' difficulty understanding food labels and maintaining good glycemic control. This project explored associations between race, literacy, numeracy, self-efficacy, self-management behaviors,

and glycemic control in diabetics, using in-person interviews combined with a series of measurements to assess literacy, numeracy, glycemic control, and other parameters. Structural equation modeling revealed that numeracy, and not race, was predictive of glycemic control and that self-efficacy was both a strong predictor of self-management and a mediator of the relationship between numeracy and glycemic control.

Preliminary Results of the Baltimore Health Literacy and Oral Health Knowledge Project

Dr. Mark Macek, University of Maryland Dental School

Relatively few studies have analyzed the association between health literacy and oral health outcomes. This project aimed to develop a valid/reliable instrument to assess basic oral health knowledge. The instrument was then used to assess basic oral health knowledge in a low-income population of adults. Study participants' health literacy was evaluated using the Rapid Estimate for Adult Literacy in Medicine (REALM), the S-TOFHLA, and oral health knowledge surveys. In addition to generating a research instrument that may be useful in other settings—the Comprehensive Measure of Oral Health Knowledge—this project suggested that word recognition or reading comprehension does not correlate highly with oral health outcomes, suggesting that reading ability is not a primary component of oral health maintenance. Rather, oral health knowledge is as good a measure of health literacy as is REALM, independent of education level.

The Effect of Health Literacy on Medication Safety in the Elderly

Dr. Grace Kuo, University of California, San Diego

This project aimed to determine whether non-adequate (inadequate and marginal) functional health literacy impacted medication safety among elderly primary care patients. A cross-sectional approach proceeded in three research phases: i) patient recruitment; ii) medication interview and medical record review; and iii) a cognitive interview in a subset of patients. Participants had to be taking at least five different medications. The study's main conclusions were: i) over-the-counter medication was more likely to be taken by patients but not recorded in their medical chart; ii) prescription medications were more likely to be recorded in the chart but not taken by patients; and iii) Spanish-speaking Hispanics were more likely to have medications recorded in the medical chart even though they did not take them. Collectively, the data suggest that adequate functional health literacy is associated with better understanding (knowledge) of taking medications as well as self-reports of medication problems.

Panel Discussion: Actionable Research

Moderator: Dr. Sabra Woolley

Improving Health Literacy Online: Reinventing www.healthfinder.gov

Sandra Hilfiker, U.S. Department of Health and Human Services

The award-winning Federal web site for consumers, www.healthfinder.gov was developed in 1997 by the U.S. department of health and human services, together with other Federal agencies. The site links to carefully selected information and web sites from over 1,500 health-related organizations. Although www.healthfinder.gov was the first web-based government health portal site, in recent years, the need for a purely ‘portal’ site has diminished with the popularity of search engines like Google and Yahoo. Efforts to redesign the site have been informed by a range of resources including literature review, descriptive content analysis, structured interviews, mental models research, card-sorting, prototype evaluations, and usability studies.

To revamp the site, the team aimed to recruit a range of end-users but encountered difficulty recruiting individuals with limited health literacy for usability studies. In general, these people are not typically part of the participant pool of most research recruitment firms. Partnering with adult learning centers, senior centers, community health centers, or other healthcare facilities that primarily care for the uninsured proved to be an effective strategy for recruitment.

Usability studies led to the design of a “Basics, Benefits, Action” formula for arranging the site’s content. This approach enables users to find information, understand its personal value, and then take a health-related action. The revised design attempts to accommodate limited literacy users with a simple layout, large font, and simplified presentation of search results. Outreach to community outlets includes clever, portable instruments such as posters, conversation scripts, and printed cards to promote the use of www.healthfinder.gov.

Lessons Learned:

- Partnering is essential.
- Combine communication and usability principles and methods.
- Information architecture is as important as the words themselves.
- Personalize content and presentation whenever possible.
- Go where people are.

Health Literacy is Fundamental to Cancer Control

Dr. Terry Davis, Louisiana State University Health Sciences Center

Louisiana has been termed the unhealthiest state in the U.S., due to high poverty, a general shortage of health care providers and clinics, and low literacy. Dr. Davis aimed to determine whether low literacy itself affected health outcomes via effects on cancer screening.

A 5-year, three-arm randomized controlled trial in six Federally qualified health centers (FQHCs) aimed to answer this question by determining whether health literacy interventions can improve initial and repeat colorectal and breast cancer screening. The study: i) compared the effectiveness of an intervention, with and without a nurse case manager; ii) evaluated the efficacy of interventions to improve knowledge, beliefs and self-efficacy toward cancer screening; and iii) explored patient, provider, and system factors that facilitate or impede initial and repeat screening.

Educational materials, provided in one arm of the study, were developed in conjunction with patients and providers, and were targeted to a 3rd, 5th, or 6th grade reading level. Short (3-4 minutes) videos were similarly tailored to target populations and were engaging, contained some humor, and included a physician in a role other than as a “talking head.” Baseline interview findings revealed a range of misconceptions about cancer screening tests; participants cited them as “uncomfortable,” “embarrassing,” and “a lot of trouble.” Many patients did not understand the appropriate timing for screening, or the need for re-screening throughout life.

Lessons Learned:

- Clinics like to participate in research but are focused on patient services and funding.
- FQHC staff and administrators lack understanding of the structure and consistency needed in research.
- Investigators need to understand a clinic’s system and culture and then work with staff to embed research in it.
- Investigators need an ongoing relationship with staff, administrators and study personnel.
- Frequent on-site visits to clinics are essential.
- Research personnel need good people skills.
- Physician turnover is common in FQHCs.

Interdisciplinary Research in Health Literacy

Dr. Sunil Kripalani, Vanderbilt University Medical Center

What disciplines should be involved in health literacy research? Experience with the ongoing Pharmacist Intervention for Low Literacy in Cardiovascular Disease study involves a collaboration of physician-scientists, pharmacists, international health experts, behavioral scientists, economists, psychologists, sociologists, statisticians, and health economists.

Patient safety can suffer at care transitions like hospital discharge; at these times, medical errors and adverse drug events are most common. Many of these errors have been associated with poor communication; thus, can they be prevented or ameliorated through interventions? The greatest risk is in elderly patients with low literacy, and this study aimed to determine if pharmacists can help avert the bad consequences of medical errors.

This study will assess the effects of pharmacist-assisted medication reconciliation, inpatient pharmacist counseling, low-literacy adherence aids, and tailored telephone follow-up about serious medication errors after hospital discharge among patients with cardiovascular disease at two academic teaching hospitals. Baseline data that will be collected from study subjects includes sociodemographic factors, medical co-morbidities, cognitive function, education, health literacy (as measured by S-TOFHLA), and understanding of pre-admission requirements. The study is ongoing, recruiting patients at a rate of about 20-25 per week.

Lessons Learned:

- Cross-training and “cross-fertilization” of ideas and expertise is important.
- Look for collaborators outside your field, and submit a grant as co-investigators.
- Mentor, co-mentor, and be mentored.
- Hire diverse research staff.
- Diverse perspectives inform various aspects of the research.
- Develop effective communication within a research team.
- Effective management is important for utilizing a research team’s diverse skills.

Discussion Themes

Communication

Effective communication is challenging but key to interdisciplinary research that crosses the boundaries of many fields. Frequent contact between researchers, study participants, and “end-users” is also tal. Personalized approaches can be extremely effective in delivering health information.

Partnerships

Health care systems can provide both barriers and opportunities for accessing health information. Understanding community culture is essential for dissemination and implementation of useful health information.

Breakout Session: Plain Language (update and future plans)

Co-Facilitators

Joanne Locke, MAS, *Office of Disease Prevention and Health Promotion, DHHS*
Qing Zeng-Treitler, PhD, *Harvard Medical School*

Questions

The co-facilitators presented the following questions:

1. What is the current status of plain language?
2. How can we evaluate progress in plain language?
3. What needs to be accomplished to advance the development and dissemination of plain language?

Discussion

Current status of plain language

- A bill passed the House of Representatives last year mandating (but not enforcing) the use of plain language in information for consumers. However, it did not reach the Senate floor for a vote. We understand it will be reintroduced in the new Congress.
- Two major organizations that promote plain language in the United States are the Plain Language Action and Information Network (PLAIN) and the non-profit Center for Plain Language. Two international organizations that promote plain language are Clarity and the Plain Language Association International.
- About 20 to 30 countries support plain language. Canada and England have very strong plain language programs. Involving the EU to a greater extent would be a huge step in the right direction.
- Plain language means you can find the information easily, understand it, and use it the way you wish to use it in the amount of time you wish to give it. It is very audience specific: Different techniques work for different groups.
- “Easy to read” does not necessarily mean easy to understand.
- There is a correlation between shorter words/sentences and readability, but that is not always the case. A document should have a reasonable length (shorter is not necessarily better), cohesion, and understandable vocabulary (although sometimes complex words, such as names of conditions, are unavoidable).

- Readability (grade level) tests are not the best way to test for understanding. It is more important to have members of the target audience read the material and do one-on-one iterative testing to find out if materials work.

Evaluating progress

- We hope to be able to make a business case for how we can help patients – e.g., better medication compliance – but this is not always feasible.
- The communication of information is separate from whether it is motivational. Plain language is necessary, but it is not sufficient to get people to change their behavior. Giving people understandable information does not always motivate them to take an action.
- Healthfinder measures self-efficacy to see whether information increases people’s confidence in taking action. Can people take the information and act on it today (e.g., substituting water for soda vs. designing an entire weight loss plan)? If not, they are less likely to do it.
- You cannot even think about behavior change or the motivation to do something unless you understand the information.
- We cannot test everything on a large audience. What is the gold standard? How many people do you need, and of what cultural background?
 - It depends on what you are trying to accomplish. In usability testing, you get similar results after the first several people. Having numbers and significant samples is important, but you can learn a lot from very few people.
 - It depends on what you are testing. Usability testing of a website is one thing, but testing whether people understand complex messages such as personal health records is another.
- Discharge instructions are very hard to understand, especially when people have multiple conditions. Knowing these instructions are not understandable is one thing; knowing how to make them better is a hard task. How do we get those who develop discharge instructions to do a better job?
- Scientific/legal departments require certain language in order to be “correct” and “accurate.” This is a barrier to plain language.
 - We can gain the cooperation of subject matter experts by showing them evidence of what does not work. For example, when subject matter experts saw how people reacted to Healthfinder content that was made too complex, the experts helped improve on wording they had previously provided.

What needs to be accomplished

- Share successes.
- As with health literacy, the field has to mature. Definitions and approaches need to be refined and tested further
- Plain language guidelines must have real-life usefulness and results.
- Working with electronic readability software forces us to be more specific and to examine guidelines. If we literally and blindly follow guidelines (removing passive voice, etc.), it can generate poor documents; however, computerized guidelines can serve as a useful initial quality check.

Breakout Session: Dissemination (of findings, leveraging change, having an impact)

Co-Facilitators: Dr. Miyong Kim, Johns Hopkins University School of Nursing; Dr. Lee Sanders, Miller School of Medicine, University of Miami

Discussion Themes

What opportunities and barriers affect the dissemination of advances in health literacy on multiple levels?

Small sample sizes in health literacy research studies limit the generalizability of the findings and thus hamper dissemination efforts. Communication and data sharing is another barrier: Many well-developed materials have not been widely shared with other researchers and as well as with end users.

Potential solutions include establishing a clearinghouse for health literacy research results or requiring NIH-funded health literacy grants to include an explicit dissemination plan. Other ideas include encouraging Material Transfer Agreements for sharing the results of health literacy interventional research, as is standard practice for biologically based/molecular research. It is important to build cost-effectiveness into health literacy interventional studies; however, cost distribution across the research spectrum can be challenging. The cost savings of an intervention are often difficult to parse.

How can our current knowledge of health literacy inform intervention strategies and have an impact on quality of life and on the reduction of health disparities in general and special populations?

It is important to understand consumer demand for health literacy interventions. Buy-in from the public and provider communities is essential for uptake of evidence-based information. To that end, more NIH funding of health literacy intervention effectiveness studies (versus efficacy studies) may enhance the dissemination of research results.

Given the changing policy landscape that is likely to dominate the coming years, it is important that health literacy researchers do not design interventions for the current health care system. However, in the absence of specific information about what is to come, tailoring interventions for future use is difficult in a practical sense. Incorporating health literacy components into institutional quality improvement programs can be useful.

Many communities have strong cultural beliefs and traditions and reject any proposed intervention that they did not have a hand in developing. Thus, it is best to incorporate community-based input at the earliest stages of research planning. This approach promotes “ownership” in health and associating decision making practices.

What comparative studies could be conducted to investigate patient/consumer use of linguistically simplified health information versus information revised using a more ecological model of health literacy (incorporating sociocultural and scientific literacy domains)?

Adding a health literacy component to larger studies investigating a range of health conditions can enable tailored health literacy research as well as pave a path for targeted interventions and dissemination. The practical difficulty of achieving this synergy is that research institutions still operate under “silos,” which can make coordinated efforts between schools and departments challenging.

One example of a successful dissemination strategy is Project SHARE⁴ (Sharing HIV/AIDS Research Efforts), a collaborative information exchange effort between the Miami-Dade County Health Department Office of HIV/AIDS and the University of Miami Drug Abuse and AIDS Research Center. This seminar series disseminates theory-based HIV prevention intervention strategies that scientific studies have shown to be effective to the South Florida HIV/AIDS service provider community. The project also provides the opportunity for researchers to share their findings, hear the concerns of community providers, and to identify new areas for future research. The seminars are videotaped and distributed to interested parties throughout the state.

There is some debate over whether interventional research instruments should mimic the real-world scenario they are investigating. One question for consideration is whether research instruments such as questionnaires and travel to clinics should be part of the intervention itself, such that the testing phase is as realistic as possible.

⁴ Project SHARE. Accessed December 18, 2008 at <http://ssrg.med.miami.edu/x26.xml>

Breakout Session: Interdisciplinary Nature of Health Literacy

CO-FACILITATORS:

Christina Zarcadoolas, PhD, *Mount Sinai School of Medicine*

Susmita Pati, MD, MPH, *Children's Hospital of Philadelphia*

PARTICIPANTS:

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Among the issues addressed during the discussion were: 1) what disciplines should be involved in health literacy research and what strategies can be utilized to enhance the interdisciplinary nature of health literacy; 2) how can an interdisciplinary team approach answer the question of why some health outcomes are related to health literacy and others are not; and 3) which steps in the disease pathway are explained by an individual's health literacy and how can an interdisciplinary approach inform the science and lead to more effective interactions.

The main discussion points are highlighted below.

Hierarchy and Components of Health Literacy

- Health literacy has concepts incorporated in health communication. Is there a hierarchy in knowledge? Does health communication fit under health literacy?
- There are lots of components of health literacy: multiple domains could suggest multiple disciplines can be the major focus –communication might be one, but if the focus was, for instance, mental health or physical health, the focus could be another discipline. There is no automatic way of deciding what the hierarchy should be.
- What gets foregrounded at any given time? For example, there are the risk communicators, people that work with risk psychology and risk perception. There are other people that work only with risk communication, but risk communication is informed by what people think risk is. Also, there is a cultural perception of risk. How rich is the question, how inviting it is to other disciplines, and how willing are health literacy researchers to give up some of the footing to other disciplines' way of thinking –all determine the hierarchy.

Multidisciplinary vs. Interdisciplinary Approaches to Health Literacy

- There are multidisciplinary teams *vs.* interdisciplinary teams, and also people cross-trained in multiple disciplines (*i.e.*, a one-person interdisciplinary team). There is no definitive analysis of how or what is supposed to go into a team, even though there is a lot of knowledge about how a team works, who should be the leader. However, there is a need to start thinking about what is it that other disciplines add.

- If the team is diverse enough, people are not prone to reinvent the wheel. For example, trying to measure functional health literacy, sociologists worry about contexts; the primary social connections –the point of health literacy– is ultimately the intervention.
- In nursing schools there is an interest in symptoms management: what are the kinds of issues and how can symptoms management be improved? Health literacy is one component. Hence, when the team is assembled, the leader of the symptoms management team is the nurse. Other disciplines are incorporated in the team, based on the specifics of the intervention needed; for example, when addressing symptoms management of prostate cancer, a neurologist, a health educator, and a health systems researcher are included in the team. The phenomenon of interest is what drives the composition and the leadership of the team assembled for that particular case.
- People in the health literacy universe are working on questions that speak to the basic behavioral and social sciences (BSS), but there may not be a lot of real interdisciplinary connections, even though the representatives of the basic BSS are contributing to this field.
- Formal education needs to be addressed when talking about health literacy. Formal educational opportunities govern health disparities. Little is known about formal education and the science involved, but this is the sort of interdisciplinary partnership that is going to be very important.

Is There a Discipline of Health Literacy?

- If one looks back for the past ten years at the questions generated in grants on health literacy, they range from perception, understanding, behavior; yet, there are very few representatives, until recently, of experts from the fields of behavioral psychology, perception, or social psychology. The field has not been represented by the thinking one would expect would be needed to answer the questions researchers posed.
- Are there any theoretical underpinnings for anything done in the field of health literacy? What are the theories that propelled researchers to think about these important questions? Are any of the meeting participants "health literacisists" or rather all belong to different disciplines (*e.g.*, nursing, medicine, sociology, *etc.*) and have come together, recognizing that health literacy, health communication are important to the goals of their disciplines?
- There is no discipline of Health Literacy, there is no body of knowledge that is specific to it. Not all public health experts speak the same language, because of the training they have, and that leads sometimes to miscommunication. In a team, it takes time to start speaking each other's language and communicate.
- Health literacy is not a discipline, it lies at the intersection of multiple disciplines.

Theoretical Models of Health Literacy

- Health literacy is thought of by researchers as an underpinning of some of the common theoretical models, *e.g.*, the health-behavioral model. These models help people make decisions about risk, or make decisions about the barriers that relate to literacy. Health literacy researchers work within the same models that the public

health people and the health marketing people do, but see health literacy as being an underpinning of the factors that are involved in those broad models.

- Health literacy is also perceived as two different trajectories: one trajectory is a multifaceted, very rich, very complex path which leads to richer, more meaningful answers while taking into account different factors (*e.g.*, domain knowledge, culture, community resources); the other trajectory is a simpler path which potentially leads to useful health literacy tools in response to pragmatic challenges (*e.g.*, making progress towards screening instruments). These trajectories are not mutually exclusive and this is part of the duality of health literacy research.

Addressing the Divide between the Health Community and Academia

- There is a big divide between the health community and the schools of Arts and Sciences community, which is very counterproductive, because people do not understand that they need each other's skills. For example, the field of social epidemiology started out on its own to develop an epidemiology that would address the social factors in health; there were very few people from the schools of Arts and Sciences that actually participated in that effort.

Improving the Grant Review Process

- As a reviewer, it would be very helpful to have potential grantees elaborate on their theories and constructs behind an intervention.
- As a potential grantee, it would be helpful to make the review panels explain what are the theories, concepts, and constructs behind grant review.
- For instance, to be constructing *e*-based interventions that don't use human factors engineering theory –one would never get funded in the technology field if they did not use it, and yet that never comes up in any review panels.

Health Literacy Paradigm Shift

- Since health literacy is not a discipline on its own, it could be infused in almost everything else, which flips the hierarchy: health literacy is not on top, instead is a part of the overall process in understanding disease of any kind.
- Health literacy being a problem to be worked on, as opposed to a discipline, actually positions it better for the coming era. At this point in time, the disciplinary structures are serving less and less of a purpose, and getting in the way of solving important questions about health. Being part of a problem-focused field is a real advantage.
- Health literacy is a set of problems, as well as a set of opportunities. Since language and culture are seen as a barriers, health literacy has been identified as a deficit or "what people cannot do". People have very rich things that they are doing with health information; may not be what researchers want them to do, but until research explains what they are doing and why, health literacy is going to be a "deficit" problem.
- Thinking outside the "tool": there is a need to have the tools to measure indicators of health literacy, but what is the concept behind the instrument/tool? How does the concept fit in the larger sphere of all those studies and models of health?

Researchers tend to put everything into health literacy, even if it does not belong here.

Approaches to Designing Interventions

- If underlying cognition at some level is measured, it should result in a totally different intervention, compared to a test measuring underlying personality traits such as conscientiousness. It is important to understand the cause and mechanisms in order to design the right intervention.
- Simplify the basics of language.
- Health education is poor in elementary schools through high schools, and has been like this for a very long time; this is a deep structural problem in health literacy, but because it is not really on the table is hard to make it an actionable, policy issue. Almost everything impacts health literacy –certainly nutrition impacts health literacy; is there a way to define a scope? Could researchers predict what is the system prepared to act on now? If a certain issue falls under the scope of what a team of researchers are currently working on, to address the policy aspect, they should also be doing research that is going to feed back. To impact the policy, researchers need to think about where does the intervention need to go in the future.

Summary and Conclusions

- Health literacy is not a discipline. There are many opportunities for researchers from many different fields to contribute and address problems and challenges and think about new ways to design interventions.
- Health literacy represents a set of problems; some of these problems may need to be addressed perhaps at an individual order, others may need a more systematic type of intervention. An interdisciplinary approach is probably required in order to do both effectively and not fall into the trap of reinventing the wheel.
- Health literacy can be improved by research and thought that promotes improvement in the current system, and in parallel by research that actually creates new systems, new paradigms.

Panel Discussion: Special Populations

*Moderator: Dr. Helen Meissner, Office of Behavioral Sciences and Social Research,
National Institutes of Health*

Literacy and Cognitive Abilities Among Elderly Persons: Implications for Intervention Design

Dr. David Baker, Feinberg School of Medicine, Northwestern University

The S-TOFHLA test of reading fluency is associated with the ability of older people to perform common cognitive tasks. Research has shown, however, that the S-TOFHLA is associated with performance on cognitive tasks hypothesized to be unrelated to reading fluency. Studies have also shown that cognitive abilities, particularly short-term memory, are independently associated with mortality and explain about half of the observed association between reading fluency and mortality.

Based on the importance of cognition for survival as a person ages, interventions to improve health education, self-management skills, and health behaviors should pay attention to cognitive load, the need for abstract thinking, and other factors that may affect comprehension and recall. Rewriting materials in plain language, while important, may not be sufficient. Rather, designing health education materials should involve the identification of “building blocks” that are taught first and re-introduced, along with identical text and images. Creating “schemas” or information categories can increase recall substantially. The same principles apply to numeracy skills—providing building blocks that “discover” an answer in a stepwise fashion can be very effective.

Lessons (to be) Learned:

- Are interventions that pay attention to cognitive factors more effective for patient education, improving patient self-management skills, and promoting behavior change?
- What does the S-TOFHLA really measure: Information processing speed?
Working memory?
- What is the best way to measure cognitive skills?
- Does reading fluency decline with age, and is this due to decline in specific cognitive abilities?
- Is decline in reading ability a marker of aging?

Health Literacy in Vulnerable Populations: A Medical Anthropological Perspective

Dr. Susan Shaw, University of Arizona

What is the influence of culture on health literacy in diverse populations?

The National Center for Cultural Competence defines culture⁵ as “the integrated pattern of human behavior that includes actions, communication, beliefs, values and institutions.” However, another definition considers the role of knowledge by defining culture as “learned patterns of thought (knowledge) and behavior shared by a social group and acquired through acculturation.”

Cultural beliefs can have a profound effect on health, and Dr. Shaw noted that “there is no culture-free way to think about disease,” since researchers live and work in their own culture of science. Language contains embedded beliefs about chronology and causation, and cultural norms define behaviors such as deference to medical personnel. Thus, literacy measures are complicated by these cultural issues. To that end, the TOFHLA numeracy quotient is the only consistent score across ethnic groups (although it has not been normed or validated for Vietnamese-speakers).

Lessons Learned:

- Providers can use universal approaches to promote health literacy and cultural competence, such as communication tools and medical interpreter for limited English proficient patients.
- Providers should learn about patients’ cultures and health beliefs.
- Health literacy researchers should use qualitative pre-testing to explore patients’ understanding of instruments.
- Health literacy researchers should learn about patients’ diverse cultures and health beliefs.
- Health literacy researchers should back-translate instruments for accuracy or use outside proofreaders.

Exploring Oral Literacy Burden in Medical Dialogue: Predictors of learning among analogue patients with restricted and adequate literacy skills

Dr. Debra Roter, Johns Hopkins Bloomberg School of Public Health

Health literacy burden in print is widely recognized. Although some print materials, such as informed consent documents, have been adapted to meet the needs of low-literate patients⁶, the reading level of many health education materials for diverse patient and community populations far exceeds average reading skills.

Most literacy measures are print-based, and oral literacy is not frequently examined outside of early childhood or a condition-related disability. Dr. Roter described her research exploring the manifestation of oral literacy burden within the context of genetic counseling practice and its effect on analogue patient learning. The language of genetics is complex and largely unfamiliar to the lay public, and genetic counseling sessions tend

⁵ National Center for Cultural Competence. 2001. Cultural Competence Health Practitioner Assessment. Washington, DC: Georgetown University Child Development Center.

⁶ Paasche-Orlow MK, Taylor HA, Brancati FL Readability standards for informed-consent forms as compared with actual readability. *N Engl J Med.* 2003;348:721-6.

to be long, informationally dense, and abstract. Her study employed genetic counselors from the U.S. and Canada to conduct prenatal genetic counseling sessions with simulated clients trained to consistently portray a scripted case. Videotapes captured the sessions and were coded to create measures of informational context and dialogue interactivity. The “analogue clients” were subjects recruited from Baltimore and Salt Lake City to watch the session videotapes while imagining they were the session client or spouse.

The study results showed that the genetic counselors’ use of medical jargon and complex language was inversely related to self-ratings of informational effectiveness. Interactivity and contextualized information was especially important for low literate learners. Overall, the results suggest that a reduced oral literacy burden carries an informational and perhaps organizational cost.

Lessons Learned:

- Oral literacy burden can be measured, and the domains have face- and predictive validity.
- Learning is associated with patient literacy and the oral literacy burden of the medical dialogue.
- Literate learners learned less in high interactivity sessions perhaps because this type of presentation style is less comprehensive or well organized than dense talking blocks.
- A broad spectrum of sociocultural and socioemotional factors may also play an important role in patient learning.

Discussion Themes

Culture

It is difficult to disentangle the roles and influences of language and literacy. Language in particular can be laden with multiple meanings, especially in populations for whom English is not the primary language. Beliefs, customs, and social support structures can influence health understanding and actions.

Methods

It is important to appreciate the world through a patient’s individual “lens.” Assumptions about knowledge and behavior can deter research validity. Learning styles are different, and research instruments should accommodate these distinctions.

Breakout Session: Cognition/Age

Co-Facilitators

Michael Paasche-Orlow, MD, MA, MPH, *Boston University*

Dreena Waldrop-Valverde, PhD, *University of Miami, Miller School of Medicine*

Questions

The co-facilitators presented the following questions:

1. What is the relationship between neurocognitive limitations and health literacy?
2. Is health literacy skill believed to be an “innate” characteristic of a patient? How does a patient’s health literacy level change over time (not specifically in relation to an intervention)?
3. What is the best way to measure cognitive skills in health literacy, and how can these measurements be used in people whose first language is not English?

Discussion

Relationship between neurocognitive limitations and health literacy

- The bulk of the curve for U.S. adults with limited health literacy is due to the failure of educational attainment. What portion of this problem is related to cognitive issues?
- There is no reading center in the brain. Multiple areas have to interact to read – e.g., the brain works differently with a pictorial language like Chinese than with a phonetic language like English. Early intervention helps the developing brain. Low SES children have not had early enough intervention and therefore have different brain development.
- One woman who never went to school could not even read an eye chart. Was she dyslexic, or did her brain not develop because of lack of exposure?
- Neurocognitive limitations would place a ceiling on health literacy, but they are not the same thing, and you would address them quite differently.

Whether health literacy is innate, and how it changes over time

- When working with older patients, you need to know whether the cognitive issue is new or pre-existing, perhaps life-long.
- Aging diminishes the ability to employ the set of resources that help one function as a health-literate individual.

- Why does it appear that reading ability declines with age? A study suggests this has a straight linear decline at a certain point. The frequency of reading behaviors does not appear to have an effect. Multimedia can be very helpful, but elderly persons with slow information processing speed cannot handle it.

Best way to measure cognitive skills in health literacy

- The whole notion of measurement in health literacy was conceived as a screen. How much ancillary measurement do you want to do? Beyond measuring neurocognitive functioning, there is also motivation, emotional arousal, etc. What is the utility of having a reasonable screen to find out what is going on? How much additional variance is enough to justify all of the cost and time to do ancillary measurements?
- We need to get a handle on what health literacy is. Literacy has always been more of a cultural convention than a construct. We have ways to measure it, but it is hard to define it as a single construct or even limit the kind of family of constructs. It is in part where we draw the boundaries. For example, do we want to have measurements that try to parcel out cognitive ability from health literacy?
- Some health literacy measures are more prone than others to problems. For example, words in REALM (Rapid Estimate of Adult Literacy in Medicine) are retained for a long time, even late into Alzheimer's, but they lose their meaning. TOFHLA (Test of Functional Health Literacy in Adults) could be a better choice for older adults.
- Some skills that TOFHLA measures are problem solving, more abstract, higher level skills than pure reading ability.
- We need measures of cognition that would happen within a reasonable study time. What is a reasonable study time?
 - The length of time depends on what you are trying to test. For example, you do not need 5 years if you are testing health outcomes.
- The issue is what skills are related to the attainment of a given outcome.
- Part of the usefulness of neurocognitive testing is the novelty of it. Because familiarity can increase performance, this can limit the kinds of tests you can use.

New actionable ideas for NIH

- The reason we spend time measuring skills is to explain decisions and actions that individuals use to maintain health and to seek health care. We need to spend more time with the decisions and actions people take. These individuals are making

decisions for reasons that are unique to them. If we continue focusing solely on the skills side, we will always be guessing what happens after that. Pursuing both directions could lead to more robust diagnostic data on how to categorize individuals with a range of difficulties now subsumed under literacy.

- Health IT systems that are too complex can increase disparities. We need to have interfaces that are accessible to people with reading difficulties and cognitive limitations. As an example, talk and touch technology and avatars can help people understand complex concepts and instructions. When people are introduced to computers and made to feel comfortable with them, they use them, such as with a pilot study with older African American women in Boston.

Breakout Session: Limited English Proficiency and Cultural Issues

CO-FACILITATORS:

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Among the issues addressed were finding: 1) what is the best way to assess literacy among people whose first language is not English (beyond the SAHLSA); 2) how to improve health literacy measurements in populations who do not speak English (for example, not just by translating English instruments, but also by conceptually measuring health literacy in a different way; and 3) what gaps exist in understanding the role of limited English proficiency on health literacy and how can those gaps be filled.

For patients with limited English proficiency, is it really a literacy issue that they are dealing with, or is it more the cultural differences, differences in illness exploratory models they encounter that create the poor health outcome or problems in coping in the healthcare systems here in the US? Is there an effective way that health literacy can be measured efficiently for this particular group, in the same way that researchers conceptualize what health literacy means for the English-speaking population?

The main discussion points are highlighted below:

Factors Influencing Immigrants' Health Literacy

- the context in which immigrants come to this country, in terms of legal status
- the age they come to the US
- the sources of health information that immigrants use (not necessarily US-based only)
- the role and influence of immigrants' social networks, in relation to health literacy: there is the misconception that the immigrants' social networks are very strong and protective, which is not always the case; there is a need to understand to what extent the immigrants get or interpret their health information through their social networks
- the strength of the ties to their native countries

Sometimes, researchers attribute to culture what is really attributable to socio-economic status (SES) or socio-economic hardship. There is a large degree of variation, in terms of

health literacy, based on socio-economic status: what is attributed to culture issues when people come to the US is actually happening in their countries of origin as well.

Literacy vs. Health Literacy Issues

There is a need for more research - the issue is not only how to assess literacy for non-native English speakers, but how to disentangle the issue of low English proficiency from health literacy?

How much of it is a literacy issue vs. a language barrier? How can this difference be measured?

- need to tease out literacy from language; the method of questionnaire administration has to be acceptable to those groups and needs to be addressed for different populations (*e.g.*, English vs. Spanish)
- the tools used to assess literacy skills need to be real-world functional health literacy tests

In the real-world context, the family with limited-English in Miami still needs to go to a pharmacy to get medicine off the shelf having indications/contraindications written in English. There is an opportunity for health literacy research to look at each context and develop an understandable tool, an understandable mechanism that still applies to the real-world context.

Impact of the Socio-Political Climate

- due to immigration status issues, it can be difficult to find patients to participate in studies (that agree to be taped, for instance)

Researchers need to be approaching assessment as a contextual issue: the best Spanish measure of health literacy could be employed, and yet there is still going to be difficult to get patients on study, because of the socio-political climate in the United States, which is impacting the methodology used in research.

Tuning Health Literacy Tools to Specific Populations

When dealing with populations with different culture or practice belief in the illness model than the general population, health literacy has traditionally been defined from a Western point of view and also from a provider's point of view. Researchers are only now beginning to understand that health literacy is about making informed decisions, rather than making appropriate decisions (*i.e.*, from the doctor's perspective)

- is there a difference or a need to conceptualize health literacy slightly different for these populations, or the need to have high health literacy for these populations should be the same as the general population?
- rather than translating the final instrument/tool, the formatting work could be done early on, with focus on the population of interest

Researchers can try to get some conceptual issues to emerge early in the process, and have this inform the way they design the task in every step of the development, from focus on item generation to cognitive interviews, rather than just translating the tool.

Counter-example: Los Angeles clinic, where both the patient population and the clinicians come from various cultures and speak many languages; how could a culturally and language-sensitive tool or health literacy measurement be developed in such a complex, diverse place?

- there is a basic component of English tool that everybody has to have: to go to the pharmacy, to read the labels on their medicines, to understand their appointments

Health Literacy Issues from the Immigrant's Perspective

Researchers have worked with Latino immigrants focus groups, in Spanish and in English. The focus groups contained immigrants that have been here for a long time, as well as recent immigrants; the participants had a wide variety of educational levels, some were college-educated professionals, others had grade school education. The researchers wanted the focus group to explain what were the health literacy issues encountered, from their perspective.

- the importance of family members and friends in the community in explaining health information emerged from the focus group discussions
- some aspects of the way the United States' healthcare system works were unfamiliar to immigrants, *e.g.*, coming for regular visits for healthcare management, an unfamiliar concept

In their final questionnaire, the researchers tried to design items that reflected some of the focus group participants' experiences and what they viewed as important areas of health communication.

Measurement Methods, Tools, and Alternative Delivery Systems Needed to Improve Health Literacy

- using a multiple method measurement model, different items can be measured for different groups

There is a need for a core set of items that are appropriate in difficulty; however, it is possible, due to the second measurement model, to add another set of items that may be different for different groups. If the answers to the questionnaires can be scored on the same metric in the response model, the researcher has the final score, which for the same value has the same meaning, even though the participants may have answered different items on the questionnaire.

Of course measures and tools are needed, and yet, in the broader context of health literacy, there are other venues and delivery systems for raising awareness and improving health literacy, some of them not in line with academia and the tenure process:

- theater performances in a community
- free transportation to doctors' offices
- delivering healthcare to communities rather than requiring people to go to the clinic (*e.g.*, vaccination rates are higher if they are delivered to the infants' homes)

Misconceptions

- populations with limited English proficiency, once they are culturally adapted, reach similar levels of health literacy as the general population
- if people have a basic level of English (*i.e.*, can read and understand health terms), they would then behave the way researchers expect them to

Behavioral vs. Cultural Factors Impacting Health Literacy

An intervention completed in Argentina was discussed by the breakout session participants, about SES-based clinical guidelines and how they were put into practice. The focus of the intervention was on the interaction between obstetricians and pregnant women: in Argentina, the physicians are the ones making the decisions about labor and delivery, while the women are not involved in the decision process. The researchers did focus groups with the pregnant women; it turned out that the women did not want to know more about giving birth, they actually wanted their doctors to be the ones making the decisions.

- knowledge created anxiety (about labor and delivery in this case) and was rejected. Much to the researchers' disappointment, the intervention was done without any patient activation component at all, without any patient education. The outcomes were excellent in this project, in terms of physicians' education, but there was no patients' education at all, which was interpreted by the US researchers as an illustration of cultural differences in how much health information people really want. However, this behavioral aspect might not be due to cultural differences, but simply due to coping styles. Even among the US-born native English speakers there are people who prefer to have less vs. having more health information, due to their different coping styles.
- need to use interventions based on peoples' coping styles, as opposed to their cultural backgrounds

Cultural Sensitivity

Researchers discussed the case of a missed opportunity due to a lack of cultural sensitivity: the state of California wanted to implement a birth-defect screening program. Folic acid was added as a supplement in many foods, *e.g.*, in cereals, but not in tortillas, a main food staple for Hispanic women, which resulted in missing this whole population, initially targeted by the intervention.

Summary and Conclusions

One of the issues that were brought up was how culture functions in this group. It seems that the general consensus is that patients with limited English proficiency have specific needs, their cultural ideologies, that ought to be addressed, understanding their level of health literacy as well as their practice of their health behaviors, which interfere or are coordinated with their health literacy.

Regarding the measurements for health literacy for these people or groups with limited English proficiency, by recognizing the complexity of the phenomena and issues involved, perhaps different researchers will end up with their own specific focus, either theoretical or real-world focus, that meets the particular needs of their target population, as well as disease needs, specific health literacy as well as general health literacy.

All English language tools used should be culturally adapted, not translated, for the populations with limited English proficiency. The opportunity for researchers that are attending to the issue of culture, but more importantly, their worldview as related to health literacy, is that if the individual (immigrant or foreigner) is given a tool which is either personalized or customized, then the information would not be translated, but

perhaps adapted to give researchers a better meaning, enabling better communication and understanding.

The researchers recognized that larger social network contexts (*i.e.*, family and friends) influence these particular groups of people with limited English proficiency. Another human agent that could have been considered is the healthcare provider; how do providers –who are not researchers and do not have a theoretical focus– respond to the low literacy or the lack of health literacy in this population may be something that needs to be addressed in the future.

Breakout Session: Socioeconomic Status/Location

Co-Facilitators: Dr. Mary Lawlor, University of Southern California; Dr. Ian Bennett, University of Pennsylvania School of Medicine

Discussion Themes

What influence does socioeconomic status (SES) have on the literacy of a population, and how should that knowledge be factored in with the measurement and evaluation of health literacy?

SES represents an array of features including income, occupation, and education. Whereas many studies, including but not limited to health literacy, aim to “control away” the influence of SES, many economists and other researchers urge dedicated study of the endogenous issues that drive SES over a person’s life course. One participant noted a study that identified a low SES population with uniformly low literacy. This population of men also were uniformly uninsured, raising the notion that uninsured status by itself may be a significant risk factor for poor outcomes.

Low SES contributes to general disenfranchisement with society, complicating the ability for health literacy interventions to reach vulnerable populations. Many features such as SES, low literacy, and general distrust of authority, may themselves be interrelated and prone to affecting other behaviors, such as the ability to communicate and receive messages.

How do settings (urban, rural, and suburban) influence health literacy, its measurement, interventions, and dissemination?

Measures of SES do not often take into account the fact that it is a dynamic entity. Thus, research models that capture the changing nature of SES may more realistically assess its role and influence in literacy, health, and other features. A corollary to this idea is that health literacy interventions for older people cannot effectively target the numerous influences, including changing SES, that occur over time and cause progressive “injury” to literacy and other social and behavioral health outcomes. Nonetheless, many view that literacy may be modifiable throughout life, whereas SES is less prone to purposeful manipulation.

Discussion touched on the possibility of mining the NALS data to tease out potential relationships between location and health literacy. Where a person lives affects many aspects of his or her life that bear on health literacy including the strain of population density, social cohesiveness, and access to health care and information technology, just to name a few.

What gaps exist in understanding the relationships between SES, location, and health literacy, and how can those gaps be filled?

Potential approaches to growing the research base to understand SES and health literacy include longitudinal studies assessing education, literacy, and health status, to search for potential links as well as research to investigate relationships between location (urban, rural, suburban) and health outcomes (although the number of confounding variables makes this complicated).

Concluding Remarks

Dr. Helen Meissner

Dr. Meissner thanked attendees for a stimulating meeting and encouraged the group to continue to pursue creative approaches in health literacy research in the face of changing times:

- U.S. demographics are shifting—minority groups will compose almost half of the nation’s population by 2050; the biggest rise in numbers will be Hispanics.
- Blacks and Hispanics are twice as likely to live in poverty as whites and Asians.
- Blacks and Hispanics have lower levels of educational attainment than whites and Asians.
- Nearly one-sixth of the U.S. population speaks a language other than English at home, thus disentangling language from literacy will get even harder
- Changes to the health care system will affect health literacy efforts.

Understanding health “from cells to society” requires both basic and applied behavioral and social sciences research. This involves understanding behavioral and social mechanisms that affect health at the individual and population levels, as well as bio-behavioral-social interrelationships. Research on the transfer of basic knowledge into practice is necessary to improve health at both the individual and population levels.

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