It’s Our Problem, Not Theirs

Health literacy has been consistently defined as the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness. In this session, we examined the mistaken interpretation of the word “individuals” to be limited almost exclusively to citizens and patients. This misinterpretation may seem logical if we define health literacy as “knowing medical jargon.” However, true health literacy reflects a relationship of respect between the citizen and the caregiver in which the caregiver has the responsibility to listen and understand the citizen. The caregiver must also have the “capacity to obtain, process and understand” what the patient says and needs. In addition, as we apply health literacy to the entire communication context of health information, we face a similar confusion. The problem with health pamphlets, fact sheets, and websites is not only the reading level of citizens, but also the ability of the authors to understand to whom they are talking and how they must present information so that it is not only clear, but credible. This session focused on the mutuality of health literacy, on the responsibilities and competencies that caregivers and professional health communicators need to foster effective health literacy, and on the new measures of health literacy we need to capture this perspective.

Teetering at the Tipping Point: U.S. Government Efforts to Promote a Health Literate Society

Health literacy has been identified as a priority area for national action in the United States, first by the Department of Health and Human Services (HHS) as an objective for Healthy People 2010 (HHS, 2000), and again in the Institute of Medicine report Health Literacy: A Prescription to End Confusion. The following decade saw the achievement of many milestones that marked health literacy’s ascendency in both the public and private sectors.

The year 2010 was a banner year for U.S. health literacy policy. First, the Patient Protection and Affordable Care Act (ACA) was passed in March. According to HHS’ Deputy Assistant Secretary for Health, “Health literacy is in the ACA because health policy makers recognized that activated and informed patients are on the critical path to increasing access to coverage and managing costs- the goals of the ACA. Health literacy is mentioned dozens of times, directly or indirectly, in the ACA because policy makers understand health care cannot be reformed in any meaningful way without health literate patients.”

Second, the National Action Plan to Improve Health Literacy was launched in May, 2010. The product of a public-private collaboration that puts forth seven goals, the National Action Plan includes a myriad of strategies for achieving those goals and creating a health literate society. This roadmap reflects the current emphasis on the need to tackle system-level changes that make it easier for people to navigate, understand, and use information and services to take care of their health. HHS has not only intellectual leadership in making the conceptual case for health literacy, but has also furthered research, trained professionals, and otherwise encouraged adoption of evidence-based health literacy practices.

Third, the Plain Language Act signed into law in October, 2010 made all federal agencies practice what they preached. The law, which is not limited to health care, requires each federal agency to use plain writing in every covered document.
As the decade progresses, health literacy is becoming infused with other health and health care improvement priorities. For example, health literacy is explicitly recognized as an aspect of being culturally competent in HHS’ newly enhanced National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care. The U.S. government continues to make an extensive effort to promote a health literate society.

It Is Our Problem and We Have Some Solutions! The Maryland Model of Oral Health Literacy

In 2007, the State of Maryland was in the limelight concerning children’s dental health. This was a result of the tragic death of Deamonte Driver, a 12 year old who died from an untreated dental infection. The leadership of the state responded immediately and charged a taskforce (Dental Action Committee [DAC]) to provide a blueprint for action to address the lack of access to dental care for low-income children. One of the seven recommendations of the DAC report was for the design and implementation of a statewide unified oral health education program aimed at policy makers, parents, health care providers and the public. Our overarching goal was to decrease dental caries disparities among Maryland’s children and youth. The approach is based on the PRECEDE-PROCEED model, a comprehensive approach to planning health initiatives. This is an essential first step towards creating a sustainable multi-sectorial state program dedicated to improving and promoting oral health literacy that contributes to the state’s capacity to ensure that no more Maryland children succumb to the ravages of dental caries.

Specifically our objective was to determine what parents and caregivers, and health care professional workers know and do about tooth decay and its prevention. In addition, we wanted to know what, if any, communication skills health care providers use on a routine basis, and equally important, know what the public thinks about their health care providers’ communication skills.

We collaborated with state medical and dental professional societies to conduct surveys and focus groups of 4 provider groups (dentists, dental hygienists, physicians and nurse practitioners) to determine what they know and do about preventing dental caries among children 6 years of age and younger. We found that all provider groups could improve their understanding of caries prevention and early detection. We also conducted a phone survey of Maryland adults to determine what they know and do to prevent caries and their opinions regarding the communication skills of their dental providers. To obtain more in depth information, we conducted 6 focus groups, two in Spanish and four in English, with low income adults with young children. Collectively, we found adults greatly lacking in their understanding of caries prevention. Most assumed that early childhood caries is inevitable and must simply be endured. Partnering with the Office of Oral Health, Department of Health and Mental Hygiene, we also conducted surveys and focus groups with Women, Infants and Children’s Programs (WIC) and Head Start directors and staff to help us understand what they know and do about caries prevention.

Based on these findings, we then conducted health literacy environmental scans in 26 of the 32 community-based dental clinics in Maryland. The purpose of these scans was to determine the overall user friendliness of the health facility. Based on the information from our statewide assessment, we identified gaps in knowledge, understanding and practices regarding caries prevention among the public and all provider groups. To help close these gaps, we created English and Spanish language evidence-based tools to address them. We developed educational interventions for gravid women, parents of young children, and health care provider groups, which we share with others. We also provide in-service training upon request to WIC, Head Start and the Area Health Education Centers. Although our focus is on dental caries prevention and early detection, the model could be used for other content areas.
References


