

NC IOM Health Literacy Task Force

August 15, 2006

NC Hospital Association

Cary, NC

Meeting Summary

WELCOME AND INTRODUCTIONS

Pam Silberman, JD, DrPH

President and CEO

NC Institute of Medicine

Dr. Silberman welcomed everyone to the meeting and thanked the NC Hospital Association for allowing the task force to meet in the space. She then pointed out that a fifth point had been added to the task force charge, which was built on issues that had been raised at the previous meeting. Finally she noted that the day's agenda would focus on public programs and that later meetings will address other sectors.

PRINCIPLES FOR CLEAR COMMUNICATION

Lisa Dieter, MS

Director, Consumer Strategy & Planning

Pfizer Inc

Ms. Dieter began by explaining the motivation for Pfizer's work on health literacy. She noted that one survey indicates that 91% of patients want to know as much as they can about their health conditions and how to treat them and 90% of people prefer to manage their medical decisions as "active partners" with their physicians. The release of health information is critical to patient involvement in the delivery of healthcare. The evolving role of the patient as a partner in healthcare decisions calls for an increased need for access to health information, understandable health information, and better and more productive provider-patient interaction. From this motivation, Pfizer developed a mission to communicate motivating, useful, and understandable information about medical conditions and treatment options to help patients work with their healthcare providers and make more informed decisions about their health.

In order to address the problem, Pfizer decided to utilize the patient centered model, which focuses on the patient's perspective, covers what a patient wants and needs to know, and acknowledges the patient's readiness to learn. The intention is that better communication will improve diagnoses, treatment, adherence, and health outcomes.

The Principles Clear Health Communications (CHC) were developed in partnership by Pfizer, the Clear Language Group, and leading health experts Leonard and Cecilia Doak. The five principles include:

1. Explain the purpose: Consider the purpose and benefits from the patient's viewpoint, use the objectives to limit the content, leave out unnecessary content (what is nice to know versus what they need to know), plan the sequence of topics, and review key points;
2. Involve the reader: Create interaction with the reader, emphasize desired patient actions and behaviors, spell out realistic action steps, make it culturally/age/gender appropriate;
3. Make it easy to read: Use conversational style with active voice and common words, provide examples for difficult words and concepts, put context first, break up complex topics, present each topic in an uninterrupted layout, do not use vertical text, use road signs and chunking, keep paragraphs short and focused on a single topic, avoid long and complex sentences;
4. Make it look easy to read: Avoid reverse type/all caps/italics, use sharp contrast and large font type, include a lot of white space and no dense text, use cueing to direct attention to key points;
5. Select visuals that clarify or motivate: Select realistic visuals, omit distracting details, use graphics that contribute to the message, use action captions, and explain list and charts with examples.

A more complete explanation of the principles can be found at <http://www.clearhealthcommunication.com/>. The challenge of using the principles is that the Food and Drug Administration (FDA) regulations are not always conducive to the CHC principals. Another hurdle is the fundamental change in mindset from the physician centered model to a patient centered model. Results from a study done at the University of California, San Francisco (UCSF) found that it is possible to make an Advance Directive (AD) legal form more health literate by following the CHC principles. The study found that the AD form using the CHC principles increased acceptability, self-efficacy, and comprehension. Furthermore, 81% of those surveyed preferred the CHC principle-based AD form over the standard AD form. It was found particularly beneficial for subjects with literacy and language barriers.

The last part of Ms. Dieter's presentation focused on leadership. To be effective, health literacy efforts must be a priority of the organization's leadership. For example, Pfizer mandates that every piece of literature be approved by the CHC review committee. It is also important to involve the stakeholders early in the process and be strategic in the planning.

Comments/Questions

The discussion that followed began with questions about how to measure and know if increasing health literacy is effective. The two studies mentioned in the presentation were referred back to and a comment was made that Dr. DeWalt had more research to present regarding patient outcomes and increased health literacy. The next set of discussions that took place centered on whether or not documents should be the focus of health literacy initiatives. A study done in Vienna showed that the interaction between patient and provider also increased health literacy, thus, interactions other than written materials can increase health literacy. Finally, a discussion of market trends concluded

the discussion with the comment that other companies were beginning to follow Pfizer, but there are really no market forces to make it happen.

COMMUNITY CARE OF NORTH CAROLINA

Denise Levis, RN, BSN, MSPH

Director of Quality Improvement and Senior Consultant
Community Care of North Carolina

Ms. Levis made a presentation about Community Care of North Carolina (CCNC), a Medicaid program that began in 1998 and was built upon the Carolina Access medical home program which began in 1991. CCNC is a collaborative model between the state and local communities. In the early stages of the program, it was important to get commitments from the major Medicaid providers by sending out letters to all the providers who had more than 2,000 enrolled Carolina Access members.

The CCNC networks produce most of their own patient educational materials and when appropriate, the central CCNC program office will produce information that can be used by all the networks. Since CCNC is a state-wide program and reaches most of the Medicaid population, it will be a good resource for distributing the findings and recommendations from the health literacy task force.

She noted that all CCNC tools are produced in Spanish and English, while some local networks produce them in other languages (e.g. Vietnamese, Hmong) based on their patient population. Most patient educational material is written at a 5th grade reading level. When trying to make items presentable and more attractive to read, there is a trade off. For example, the bookmark on the home treatment of flu had a trade off between white space and the amount of information to be placed on the bookmark. The information can be placed in a variety of areas in different mediums, such as magnets, bookmarks, pictures, packets, and cups. Decisions about the way in which material is presented are determined by various means. Initially, the material is developed by visiting the intended audience. The information is then continually tweaked.

In developing a program, it is important to keep certain tenants in the back of your mind. First, the top down approach does not work. It is important to make sure the major stakeholders are at the table during the development process and for the local community to have ownership in the program. Then you have to align incentives to make the program work. Finally, it is important to measure the outcomes and ensure you are getting what you would expect. Publicity is not a key factor. In fact, CCNC did not publicize their program until they had made a significant investment into its success.

MENTAL HEALTH, DEVELOPMENTAL DISABILITIES AND SUBSTANCE ABUSE SERVICES

Michael Lancaster, MD

Chief of Clinical Policy

Division of Mental Health, Developmental Disabilities and Substance Abuse Services

Dr. Lancaster began his talk by focusing on what he termed the missing piece in health literacy: provider education and engagement. Rather than just looking at the capacity of consumers to obtain, process, and understand the material, the missing piece is how it is *delivered* to the consumer. If consumers cannot engage, they will not understand the material regardless of how it is presented.

It is also important to properly refer to a person when engaging him or her. For example, calling the person a patient may place the doctor on a higher level. It is preferable to call the person a consumer because he/she is consuming a service. The goal for printed materials for the Division of Mental Health/Developmental Disabilities/Substance Abuse (MHDDSA) is a 6th-8th grade reading level, but the Division does not assess literacy level. In terms of cultural sensitivity and language barriers, MHDDSA refers to the guidelines for the Department of Health and Human Services. These recommendations will be implemented at the state, local management entity (LME), and provider level, and everything an agency produces is reviewed by Department's Public Affairs Office. The main point to remember is that written material is a vehicle to generate discussion, not the primary means of information delivery. MHDDSA has a number of consumer and family advisory groups that review information, provide feedback, and help develop documents. Rather than trying to raise individuals' literacy levels, MHDDSA tries to work with them at their level. They have to be able to reach out to consumers in their own environments, not just in a clinic.

MHDDSA is shifting from the medical model to the consumer model. We have adopted key pieces of community based, consumer driven, evidence based practice, and best practice models. The consumer driven part of the engagement is person-centeredness in the medical sense. The success of our treatment of consumers, and particularly those in mental health, is riding on the backs of integration with primary care.

Including patients at the table during the discussions has been an enlightening process for mental health. In the midst of a policy discussion, mental health has consumers at the table who can tell them how a policy is carried out. It changes the dialogue, such that consumers tell mental health what will not work. For example, during the writing of definitions around diagnostic assessment, it is often assumed that physicians are doing the consultations face to face. The consumers noted that this is often not done in practice, so face to face consultation was made a requirement. Health literacy is not just about a piece of paper, but also about how to engage the consumer so that they are part of their own care. All the plans should be designed around the consumer's goals.

Mental health has been more involved with its consumers than many other groups because it uses a behavioral health point of view. Many mental health consumers have a

difficult time understanding the importance of their medications and other healthcare needs. What is more important than the written materials is how they deliver information and empower consumers to make decisions. If consumers don't want to take their medications, providers need to be able to explain to them why that decision is disconcerting. Engaging consumers in a conversation gives them some power and mutual respect to make a decision based on information. By giving the consumer control, they are more invested in their care. Consumers should not be afraid to ask questions because if they aren't empowered to ask questions, they are not going to be health literate.

PUBLIC HEALTH PROGRAMS

Marcus Plescia, MD

Chief, Chronic Disease and Injury Section
Chronic Disease and Injury
Division of Public Health

Dr. Plescia began by giving a brief overview of the Division of Public Health (DPH). The system for direct care for DPH is based on county health departments. There are 100 counties in North Carolina and most have their own local health department, while a few counties have small regional health departments. There are 85 local health departments and each one is unique with diversity in their approaches. There are some standards across all health departments, but there will always be some variation.

Many of the actual formats used for direct patient communication and written materials are standardized across the Department of Health and Human Services (DHHS). DHHS tends to be very oriented toward the guidelines from the Centers for Disease Control and Prevention. Education techniques depend on the type of patients being seen that day. For example, a group of maternity patients would be target with group education. DHHS is very patient focused and very family centered; looking at the family as the unit on which they try to focus. DHHS can do group and one-on-one visits through a variety of different formats.

The focus of DPH is the health of populations, rather than individuals. DPH tries to reach out to improve the health literacy of populations. One of the challenges for public health is the need for leaders to be able to communicate effectively with the public in each of the health departments. DPH has tried to put a system in place for communicating information.

Health education is achieved in a variety of ways. The most common is one-on-one communication with patients; but public health is shifting the way that health educators work in health departments to developing a workforce for making broad public messages and being able to bring people together and engaging people around policy or environmental interventions that need to happen at the community level. Public health also has regional health educators that provide assistance to the local health departments with health educators on staff at each local health department.

DHHS requires documents to be at a 6th to 8th grade reading level and have tested some materials in the realm of social marketing. One of the resources is the prism database, which can provide a wealth of information about the target population

The Division of Public Health is trying to educate students early with the healthful living standard course of study (grades kindergarten-12), which teaches children the basic elements of health and health education. The challenge is that most of the teachers are not experts in the subject area of health education. Therefore some teacher education has been conducted.

Social marketing is also a useful tool to promote health literacy. Programs such as Know Your Numbers help patients ascertain information and understand their medical condition. It is important to know the targeted population and the information they need. Then, the objective is to promote the message through various sources.

In the future, DPH will need to improve its work on communicating through interpreters, standardizing materials, and focusing on health literacy and not just literacy in general. The added challenge, however, is funding for testing and improving materials.

Discussion

The discussion after the presentation began with conversations about how the media could be distributed through various agencies and the marketing of the information. It then moved a brief comment about the reading levels that the Department of Public Health uses for its literature. Dr. Plescia agreed that the 6th to 8th grade reading level needed to be revisited.

AGING

Heather Burkhardt, MSW, CIRS-A
Information and Assistance Developer
Division of Aging and Adult Services

Ms. Burkhardt began the presentation by giving a brief overview of the Division of Aging and Adult Services. The primary focus is administering funds for the Older Americans Act, but the Division has also assumed responsibility for Adult Services.

The Division itself does not provide any direct services. Instead, it contracts the work out to local providers. The greatest strength of the Division is that it is able to provide information to its large network of providers, which do regular outreach to older adults, persons with disabilities, and their caregivers. The Division has found a lot of its clients don't make their own healthcare decisions. They depend largely on family members or trusted neighbors who they consider to be knowledgeable.

The Division depends on partners to provide information to its clients because it does not have the capacity or expertise to develop its own documents related to health issues.

Given this setup, the local communities may get their information and literature from a local hospital, the Centers for Disease Control and Prevention, health departments, or a variety of other sources. There is no standardization of the material since there is no internal review committee or any capacity to check the documents across communities.

In order to spread the message to its clients, the Division provides information in a variety of venues including conferences, health fairs, senior centers, support groups, senior theater, senior games, and speakers' bureaus.

Overall the Division is a small agency that does not have the capacity to do public relations. Rarely does it generate its own material, thus, in-house review is not much of an issue. The structure of the Division includes a program specialist for each program and they are not currently provided with communication training.

Discussion

A comment was made about the need of local organizations to be able to share materials because they do not have the resources to create their own materials.

DISCUSSION ON OPTIONS TO STRENGTHEN PUBLIC SYSTEMS TO IMPROVE COMMUNICATIONS WITH PEOPLE WITH LOW HEALTH LITERACY

Pam Silberman, JD, DrPH

President and CEO
NC Institute of Medicine

Dr. Silberman presented an overview of the ideas discussed in the meeting to improve health communication for people with low health literacy. They are outlined below:

Written Materials

- Institute a review committee charged with reviewing all materials for readability prior to use
 - However, need to establish a process that can move quickly and does not become a hindrance to the development and dissemination of health education materials
- Involve consumers and families in reviewing materials (e.g., focus groups, on review committees, etc.)
- Establish standardized criteria for written materials. For example:
 - Reading should be no higher than a 5th grade reading level
 - The materials should be easy to read with a lot of white space
 - The materials should try to motivate consumers
 - The materials should be linguistically and culturally appropriate

Other Non-Written Forms of Communication

- Need to augment written materials with face-to-face communication

- Goal is to communicate information through trained health communicators (e.g., health educators)
- Explore the appropriate use of CDs, videos, talking pill bottles, and public service announcements as other means of reaching consumers
- Explore the use of group education settings when appropriate (e.g., group prenatal care education may be culturally appropriate for certain population groups)
- Disseminate materials through other forums (e.g., community fairs, senior games, etc.)
- Explore greater use of trained lay health advisors, *promotores*, patient navigators to disseminate health information (e.g., trusted people from the community)

Involve Consumers and Families

- Involve consumers and families in developing materials and providing feedback (see written materials section, above)
- Involve consumers to ensure materials are culturally and linguistically appropriate and acceptable to the community
- Target messages to subgroups of consumers (social marketing)
- Involve consumers/engage consumers in disease management/case management

Work with Providers

- Educate providers about appropriate ways to communicate with and engage consumers with low health literacy
 - Provide communications skills training (e.g., through AHEC, public health, CCNC, drug representatives, other training opportunities)
 - Note: Different health systems use different types of providers. We are referring to providers broadly, including but not limited to: physicians, physician assistants, nurses, health educators, social workers, lay health educators, etc.
- Help train the trainers, so that communication skills training can be more broadly disseminated