Materials and Strategies That Work in Low Literacy Health Communication

SUE PLIMPTON, MPH JANE ROOT. PhD

Ms. Plimpton is a Health Educator and Director, Health Literacy Center, University of New England Area Health Education Center Program, Biddeford, ME. Dr. Root is a nationally recognized reading specialist and literacy consultant who has retired to Maine.

This project was supported by the Bingham Program, a New England philanthropy, and by Area Health Education Center Special Initiative Grants Nos. 5U76 PE 00474 01 and 02 from the Bureau of Health Professions, Public Health Service.

Tearsheet requests to Sue Plimpton, Health Literacy Center, AHEC Program, University of New England, Hills Beach Road, Biddeford, ME 04005; tel. 207-283-0171 ext 205; FAX 207-282-6379.

Synopsis.....

In a Maine Area Health Education Center program some solutions were developed to the well-

documented problem of health information material that cannot be read or comprehended by low literacy adults.

Professionals in health education and adult education were trained to produce easy-to-read health materials and created dozens of low-cost pamphlets on the nation's year 2000 health objectives. The pamphlets are easily reproducible on a copy machine.

Concurrently, a model for teaching oral communication skills to health care providers who deal with low-literacy adults was developed in partnership with Maine's largest rural health center delivery system. The train-the-trainers model reached more than 500 direct health care service providers.

Participants in the two programs gained skills useful in all aspects of public communication that are replicable in other cities, States, and regions.

EFFECTIVE COMMUNICATION is the backbone of health promotion and disease prevention. People need to understand health information to apply it to their own behavior. Most health information, however, is written for a reading level beyond 10th grade comprehension. Because 30-50 percent of the target audience cannot read at this level, they do not understand the message. Many studies that compare the reading difficulties of health materials with the skills of the reading public indicate that there is a broad gap between the readers and the materials (1-8). At the same time, many health professionals also give information orally that cannot be understood by their listeners.

The most poorly educated adults, those with the lowest literacy levels, suffer the highest rates of morbidity and mortality from chronic diseases and conditions. The fact that they cannot either read or understand the information necessary to improve their health would seem to be an important contributing factor.

Either a way must be found to develop universally high level reading and listening skills, or

communication must be improved so that most people can understand. Clearly, the latter solution is the only one possible for health professionals. Many providers and patients would welcome this simplicity. Even those health care clients who read very well prefer shorter, better focused materials than those that are currently available.

Health organizations have ready supplies of pamphlets, instruction sheets, forms, and so on, which they freely distribute. Much of this literature goes unread even by able readers because people do not have the time and high level of interest it takes to decipher them. When anyone is ill or stressed, attention and comprehension decrease dramatically. Then, even able readers or listeners have trouble understanding complex information.

For example, hospital nurse educators have told us repeatedly how difficult it is for patients to learn in the hospital environment with its stresses and discomforts. When nurses check on patients' understanding of the previous day's instructions, they often discover that they must repeat the same material.

Maine's Materials Development Effort

The search for materials. This problem—the mismatch between the level at which information is delivered and the level of patient understanding—surfaced in Maine in late 1989. Rural physicians repeatedly asked the Area Health Education Center (AHEC) (see box) for easy-to-read patient education materials. The AHEC Health Educator attempted to fill the request by contacting all the appropriate health organizations in Maine.

She heard the same response again and again, "We don't have any materials like that, but we really need them. Please find them for us too." Adult education specialists from the Maine Literacy Coalition commented, "We can teach people to read, but they can't get jobs if they don't improve their health habits. We don't have materials that our clients can read to help them improve even their basic dental and personal hygiene."

A computer search for easy-to-read materials uncovered professional articles dating back 20 years that documented the problem but few easy-to-read materials. One book did present a solution—"Teaching Patients with Low Literacy Skills" by Cecilia and Leonard Doak and Jane Root (9). The fact that Jane Root happened to be living in Maine presented the opportunity for a collaborative working relationship that has led to a unique approach to closing the health information gap in the State.

Planning a solution. In the spring of 1990, the authors, working together, came up with a possible solution—a partnership of health professionals and literacy experts to collaborate in developing easyto-read health materials. The health professionals knew the technical information and would be the primary authors, and the literacy experts knew the target audience and what kinds of material would reach them. Rural health care providers and literacy professionals both suggested that materials needed to be low-cost, reproducible on a copy machine, and culturally appropriate. These constraints, in turn, suggested a simple materials format—a single sheet of paper folded in half like a book. Finally, we envisioned implementing our solution by bringing health and literacy professionals together in a series of training sessions so they could learn how to create the materials.

Seeking collaborators. Conceptualizing the solution was the easy part. The model then needed to be shared with the major health organizations in

What is AHEC?

In 1972, as a result of a Carnegie Report on the shortage of health care providers, Congress passed legislation to encourage medical schools to establish Area Health Education Center Programs.

These educational programs were to enhance recruitment and retention of health professionals in underserved areas.

The Federal AHEC Program uses four educational strategies:

- clinical training in underserved areas for health professions students:
- accessible continuing professional education for practitioners;
- health professions student recruitment from underserved areas; and
- technical assistance to community service organizations.

The Maine AHEC Program office was established at the University of New England College of Osteopathic Medicine in 1987.

Maine, together with a request for collaborators. We reached out to public health organizations. private health agencies, and key institutions in the health delivery system. Sometimes the approach was made to front-line workers, sometimes to organization directors. We knew that participants would not learn skills in a day. They needed time, practice, and support to learn. We needed commitment for interested staff members to attend a series of four training workshops spaced about 2 months apart. The intended product would be easy-to-read materials useful in their own organizations. They would decide what materials they needed. We asked only that the pamphlets address one of the nation's year 2000 health objectives. This allowed much leeway in the choice of topics.

Some organization directors saw immediately how the training and the products would benefit them. Others had to be convinced. Initial doubts of the staff participants disappeared after the first training workshop when they grasped the significance of the problem and could see themselves contributing to a solution. Those professionals became effective missionaries to their own agencies.

Involving literacy experts. We knew it was important to get the help of the literacy professionals because they knew well the struggles experienced by less able readers. We invited professionals in adult education who worked in the vicinity of the State Capitol, our training site, to join the health professionals in a materials development consortium.

Training the materials development consortium. This initial consortium involved about 30 participants from a dozen health agencies and a half-dozen adult education programs. At the four training sessions, Jane Root, the primary trainer, identified problems in typical health materials related to vocabulary, sentence length, conceptual complexity, information overload, tone, and so forth, that make them hard to read.

She cited the following problems frequently encountered in typical health materials:

Content

- information overload
- core message not clear; desired behaviors not emphasized
- too many long words and complex sentences
- technical language or jargon, or both
- uninviting tone
- inappropriate for target audience either in culture or language

Graphics

- solid print and no illustrations
- page cluttered with too many graphic devices
- organization of content not clarified with titles and subtitles
- print too small
- illustrations do not fit the message
- cartooning body parts

Expense

• heavy coated stock and multiple colors costing extra tax dollars or grant funds

Her teaching was designed to remedy these shortcomings in typical health literature. In each training session, new information was combined with small group interaction to internalize the skills. In between sessions, health professionals would rewrite their pamphlets based on feedback received at the training. This was a "learn and do" project.

Participants were taught how to

- identify the learning difficulties of poor readers and overcome them with simpler material,
- identify the characteristics of easy-to-read material,

- include, in planning the development of material, the methodology of needs assessment and of applicability to culturally diverse populations,
- identify and use the rules for writing easy-toread material.
- use two readability formulas to check the level of written information.
- learn and practice principles of good graphic design with the assistance of expert graphic designers
- learn about and plan a process for formative evaluation (field-testing) of new materials, and
- develop a low cost, easy-to-read health pamphlet that could be reproduced on a copying machine and manage the steps in the production process to complete it.

Creating materials. At first, this writing and rewriting proved to be a frustrating process, but as time went on and the pamphlets were continually improved, patience was rewarded. As the text was developing, authors also learned the rules for good visual presentation of the text and how to use illustrations to enhance it. Although we had chosen a simple format, we knew that materials should be attractive if we expected adults to pick them up and use them. A graphic artist was engaged to help with layout and design.

Compromises were necessary to keep production costs low and the materials copy machine-reproducible. We were limited to black ink and line drawings. Colorful paper and good design added to the attractiveness, however. Books of standard generic drawings, called clip art, were used extensively to keep the costs down. Often the clip art pictures had to be modified, so they would be medically accurate. For example, dentists had to be retrofitted with masks, gloves, and safety glasses to reflect the requirements of the 1990s. The project graphic artist also freely borrowed ideas from existing noncopyrighted pamphlets, newspaper ads, and even the advertisements in the yellow pages of the telephone directory.

Testing and finalizing the product. The critical step of field testing came next. This process is frequently omitted when professionals develop materials. Although a pamphlet may be reviewed by professional peers, often the intended audience is not consulted by pamphlet developers. In the Maine model, the perspective of this user group was represented from the beginning by the literacy experts. Then the user's perspective was sought directly in formative evaluation. The adult educa-

tion professionals had access to ready-made test groups—their adult students.

The health professionals and these educators learned in training sessions how to test the readability and acceptability of the materials. Together, they tested new pamphlets in literacy classes with adult students reading at the 4th to 8th grade level. Often, pamphlets were also tested with other groups, clinic or hospital audiences of potential users or a group of parents of children in the Headstart Program, for example. Many a pamphlet went back to the drawing board after this process, and emerged with text or graphics, or both, appropriately revised.

When the pamphlet authors and the authors of this article were satisfied that the result was as good as we could make it, the artist produced the final product (the mechanical) for the printer. A local printer made a stat, a photo mechanical transfer, at low cost. This could then be copied over and over again with no loss of clarity, providing quick, cheap reproducibility.

Facing the obstacles. Producing pamphlets required patience and perseverance. Two major concerns emerged. Some participants drafted and redrafted excellent materials only to be confronted by a supervisor asking why they had "dumbed down" everything. This concern is frequently expressed when simplified materials are compared with more typical handouts. Supervisors do not want to be perceived as insulting clients with over-simplified materials. But, our experience has been that when given a choice, at health fairs, for example, even able readers choose easy-to-read materials if they have visual appeal. Some supervisors are also concerned with agency image and are reluctant to give up slick, yet hard-to-read health brochures.

The second major difficulty was getting participants to stick with the process. Occasionally, so much peer review and feedback strained the egos and required nurturing support. Time and workload could be enemies as well.

Evaluating process and product. Process evaluation has been an integral component of the project. As already stated, materials were both peer-reviewed and evaluated by their audiences for readability and acceptability. In addition, we tracked the distribution and use of materials, and contacted users for feedback. The easy-to-read pamphlets are used in hospitals, clinics, private businesses, social service and public health agencies, libraries, schools, and as instructional materials in literacy

'Either a way must be found to develop universally high-level reading and listening skills, or communication must be improved so that most people can understand. Clearly, the latter solution is the only one possible for health professionals.'

programs. The consortium participants who created them as well as the institutional users report that they are meeting the needs for which they were intended.

More rigorous outcome evaluation awaits further funding for personnel and time to assess the effectiveness of materials. One such study about smoking cessation materials supported improved comprehension for both low and high level readers when materials were simplified (10).

Written evaluations from consortium participants substantiate another result of the training process—re-energizing and skill-building of health professionals around the entire communications issue. They wrote.

I will never look at health educational materials in the same way again. This training has been so needed and I feel will have a major impact on health education in the State.

I shared this information with our whole staff. We're starting to review all our materials to see which ones we need to revise.

What I liked best is feeling that what I do as an educator has strong impact in all areas of life and feeling respected because of it. Having a product to show for my time and effort is extremely satisfying and important.

This project has changed me! I don't write anything anymore without thinking in terms of low literacy materials development.

As the comments and additional evaluation data showed, this experience produced far more than a series of pamphlets. It created capacity within participating organizations to communicate effectively with the public. These health educators and literacy professionals now use their new skills in many aspects of their jobs. They learned how important it is to communicate simply and clearly

Example of How Health Information is Simplified in Maine Health Literacy Program

Excerpt is from a consent form for HIV testing.

Before

"A positive HIV test indicates that you are infected with HIV and that you can pass the virus to other people. Inaccurate positive and negative test results occur occasionally. For this reason, a negative test result does not guarantee that you are not infected. Rarely, a positive test result is inaccurate and indicates that you are carrying HIV even if you are not."

After

"A positive HIV test most likely means that you have the HIV virus and can pass it on to others. Sometimes the test results are wrong. If your test is positive, there's a very small chance you don't really have the virus. If your test is negative, there's still a chance you may have the virus."

with everyone, whether the message is written or oral.

Many participants have trained additional staff members, and several have retooled their public presentations. One agency retrained their receptionist to answer the telephone with easy to understand words. She no longer invites people to "smoking cessation classes" but rather to "quit smoking groups." Now, almost no one has to ask, "What's that?"

Funding. Funding is always a challenge, and this project was no exception. The first year was supported primarily by Maine's AHEC system which absorbed administrative costs, provided for a small training-consulting fee, and paid for space for training and for graphic art and production costs. When money was short, people pitched in to help. Participants were not charged for training, but they had a contractual obligation to produce a pamphlet.

Our initial success encouraged us to seek additional funding to continue and expand the work. The number of requests for materials and training assistance let us know that the literacy and health promotion project was making a difference in Maine.

Project expansion. In 1991, the Bingham Program, a New England health philanthropy, awarded a grant that made it possible to double the consortium and produce additional easy-to-read materials. Between 1991 and 1993, we replicated the original training model with many new participants and offered seasoned participants advanced skills training. More than 50 health care providers and a dozen literacy participants have engaged in materials development. We broadened our products to include forms, letters, and instruction sheets that

health agencies use routinely. Oral interaction as well as written materials receive attention. New needs required us to generate new training strategies, and all of us advanced our skills in the process.

Reaching Out to Health Care Providers

Training a core team. From the outset, we realized that producing materials would address only part of the problem. We also needed a way to help those who provide direct health care improve their oral communication with lower literacy patients as well as use our materials effectively. An AHEC Special Initiative Grant funded a partnership with Kennebec Valley Regional Health Agency (KVRHA), Maine's largest rural health center delivery system. The grant provided for a part-time literacy coordinator and the development of a core training team at KVRHA. Using a train-the-trainers model, we developed the team with the understanding that it would train more than 500 KVRHA health personnel.

A first effort was to teach the team to gather data on the extent of the literacy problem in the patient population. Team members used the Wide Ranging Achievement Test, Reading Level 2, revised 1984 edition (11), with patients in rural health clinics, as well as in substance abuse and home health programs. The reading test provides a word recognition grade level score. It is brief, easy to administer in a clinical situation, and is suitable for adults. We combined test data from KVRHA patients with similar information from other Maine health agencies to produce a total sample population of 250 patients. One third of tested patients read below the 9th grade level and another 20 percent read only slightly better. The KVRHA team used readability formulas to check the health materials on the shelf and found that 75 percent of them were written at the 10th grade level or above. These results correspond with findings from other studies throughout the United States (12). Armed with this information, the team had the evidence needed to convince health care providers that a significant communication problem existed.

We worked with team members to develop strategies to address both written and oral communication. In 1992 and 1993, the team educated providers throughout the KVRHA network, emphasizing effective skills for teaching patients. Process evaluation indicated that training objectives were met. More importantly, care providers have come to the excited realization that they have new tools to reach hard-to-reach patients.

A doctoral student who has planned a project-based dissertation will assist in a future outcome evaluation. Prior research has shown that the techniques the KVRHA team is teaching care providers are effective in increasing patient understanding and compliance (13). We anticipate similar results, depending on the extent to which providers use the techniques.

Reaching a broader audience. We have extended the impact of our training experiences with both the materials development consortium and the KVRHA team by repackaging the training to meet specific needs. We have presented programs ranging from 45-minute awareness sessions for medical residents to 2-day intensive training sessions in Maine's most rural areas. We are working with staff members in State agencies to review and rewrite materials that they send to the public. A national audience attended a 3-day institute on low literacy communication skills at the University of New England in the summer of 1992 and again in 1993. The Health Literacy Center at the university will continue to offer this institute each summer and periodically during the year.

Discussion

What have we learned from all this?

The problem—the public's lack of understanding of health information compounded by the professional's lack of awareness of the issue—is broader and deeper than we had imagined. Every health-related organization with which we have worked communicates at too high a level. Not only are patient education materials hard to read, but so are forms, letters, surveys, marketing brochures, instruction sheets, and so forth. Direct health care

'Not only are patient education materials hard to read, but so are forms, letters, surveys, marketing brochures, instruction sheets, and so forth. Direct health care providers are also largely unaware of their patients' misunderstandings of oral instructions. Consequences range from noncompliance to increased system costs.'

providers are also largely unaware of their patients' misunderstandings of oral instructions. Consequences range from noncompliance to increased system costs.

Half the adult population needs easy-to-read materials, and the other half who do not need them wants them anyway. People under stress have limited ability to understand, and otherwise-able readers prefer their information brief and concise. If we are to achieve the objectives outlined in "Healthy People 2000," we must address this core issue of communicating health information so that it can be understood. It can be done.

The Maine health pamphlets have been widely requested from all areas of the country. Some materials are generic enough to fit anywhere, but most of our materials work best with rural white populations. Other regions need to produce their own appropriate versions.

We suggest that each State create one or more teams of health and literacy professionals organized to produce materials and educate health care providers. Health professionals who are not familiar with literacy professionals in their area can call the local school district office about adult basic education-literacy programs. A list of professionals for each State can be obtained on a national literacy hotline in Lincoln, NE, at 1-800-228-8813.

In Maine, many organizations willingly contributed staff time to materials production in exchange for training and materials development support for their organizations. A host institution in each State needs to provide the necessary leadership and administrative services to coordinate the effort. This leader can be a State health department, a post-secondary educational institution, an AHEC, a special task force or institute—any institution with credibility in the arenas of health education, planning, policy, and service delivery.

We also suggest that State teams in regional areas pool their efforts and share training and administrative resources. Regional collaboration can take into account varying local cultures, customs, and languages while promoting efficient collaboration and networking.

We are eager to share our experience and our materials. Additional details about the two training models, one for producing easy-to-read materials and one for providing continuing education to health care providers, as well as the materials, are available from the authors.

The health communication-literacy problem has been documented for more than 20 years. Maine has created some solutions. The challenge is to develop the national vision and strategies that could build on the Maine experience and encourage additional solutions.

References

- Boyd, M. D., and Citro, K: Cardiac patient education literature: can patients read what we give them? J Cardiac Rehabil 3: 513-516. July 20, 1983.
- Davis, T. C., et al.: The gap between patient reading comprehension and the readability of patient education materials. J Fam Pract 31: 533-538 (1990).
- Leichter, S. B., et al.: Readability of self-care instructional pamphlets for diabetic patients. Diabetes Care 4: 627-630, November-December 1981.
- Meade, C. D., and Byrd, J. C.: Patient literacy and the readability of smoking education literature. Am J Public Health 79: 204-206, February 1989.
- Michielutte, R., Bahnson, J., and Beal, P.: Readability of the public education literature on cancer prevention and detection. J Cancer Educ 5: 55-61 (1990).
- Richwald, G. A., Wamsley, M. A., Coulson, A. H., and Morisky, D. E.: Are condom instructions readable? Results of a readability study. Public Health Rep 103: 355-359, July-August 1988.
- Streiff, L. D.: Can clients understand our instructions? Image J Nurs Sch 18: 48-52 (1986).
- Zion, A. B., and Aiman, J.: Level of reading difficulty in the American College of Obstetricians and Gynecologists patient education pamphlets. Obstet Gynecol 74: 955-959, December 1989.
- Doak, C. C., Doak, L. G., and Root, J. H.: Teaching patients with low literacy skills. J.B. Lippincott Co., Philadelphia, 1985.
- Meade, C. D., Byrd, J. C., and Lee, M.: Improving patient comprehension of literature on smoking. Am J Public Health 79: 411-412, October 1989.
- Jastak, S., and Wilkinson, G.: Wide ranging achievement test, reading level 2. Revised Ed. Jastak Associates, Wilmington, DE, 1984.
- Doak, L. G., and Doak, C. C.: Patient comprehension profiles: Recent findings and strategies. Patient Counseling and Health Educ 2: 101-106 (1980).
- Ley, P.: Communicating with patients; improving communication, satisfaction and compliance. Croom Helm, New York, 1988; p. 179.