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## EVALUATING A HEALTH LITERACY KIT FOR PHYSICIANS

About 90 million adults in the United State have difficulty accurately and consistently locating, matching, and integrating information. These people are less likely to be able to obtain, process, and understand basic health information and services; they have low health literacy. Patients with low health literacy struggle with prescription instructions, medicine labels, required medical forms, have longer hospitals stays, experience poorer health outcomes, and cost the health care system billions of dollars, annually. The American Medical Association (AMA) developed a health literacy kit to help physicians meet the needs of these patients. The AMA evaluated the kit through a written survey and structured interviews with early adopters. Physicians utilized the kit in their own practices and shared the materials, especially the videotape, during staff meetings, in-service training programs, and other venues to reach more than 9700 professionals. Interviewees recommended improvements for the kit and areas for future research.

*Keywords:* medical treatment compliance, adult medical costs, patient literacy, program evaluation, physician education, health professional education.

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## 1. Background

Close to 90 million adults have literacy skills that are below a high school level (Kirsch et al 1993). This finding is based on the National Adult Literacy Survey that found that almost 50% of the adult population had inadequate literacy skills to fully function in a modern society (Kirsch 1993). The International Adult Literacy Survey, with the assistance of the Organization for Economic Cooperation and Development (OECD) in which 20 nations took part between 1994 and 1998 revealed similar results (OECD 2000). These numbers include the millions of adults who experience difficulty locating, matching, and integrating information in written tests with accuracy and consistency.

Limited literacy is now receiving attention in the medical literature because of the risk it poses for poor health outcomes. In fact, results from more than 300 studies identified that patients could not understand the medical information that was designed for them (Rudd et al 2000). Based on these findings, it is reasonable to conclude that limited literacy skills compromise patients' ability to prepare adequately for surgical procedures, take medicine on a prescribed schedule, follow medical instructions to address acute conditions, or comprehend medical terminology that describes their illnesses. These reading and comprehension difficulties result in an estimated \$50 billion to \$73 billion annually to the U.S. health care system (Friedland 1998).

Patient populations that include the elderly, minority groups, immigrants who may not be literate in their native language, and the poor are more likely to have limited literacy than patients who are not members of these groups. Persons with limited literacy have less knowledge about health in general and their medical conditions in particular; their health status is lower, they use health services at higher rates, and their health costs are higher (Weiss 2005).

A burgeoning field of inquiry, referred to as health literacy, is addressing many of these concerns. A working definition of health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Ratzen & Parker 2000). Patients with low health literacy may not distinguish themselves from other adults on the basis of their speech, mannerisms, or employment status. However, their behavior in the clinical setting is recognizable because they are less likely to complete medical forms adequately, may bring another family member

to their appointments to listen to medical instructions, or request to finish required paperwork at home (Williams 2002). Patients with low health literacy are often expert at compensating for their limited reading and/or computational abilities. To deal with the shame associated with their limited literacy, these patients guard against participating in situations that may highlight their deficiencies. Consequently, these patients have lower participation in medical decision making and are more likely to seek care at a more advanced point in the illness. Patients with low literacy are more likely to make medication and treatment errors, to have poorer health outcomes and poorer disease management skills, and to have longer hospital stays compared with patients with average literacy skills (Baker 2004, Agency for Healthcare Research and Quality 2004, Baker 2002, Gazmararian 1999, Dewalt 2004).

The American Medical Association (AMA) identified low health literacy as a barrier to effective diagnosis and treatment (US Department of Health and Human Services 2000, Ad Hoc Committee on Health Literacy for the AMA Council on Scientific Affairs 1999). Health information is distributed in complicated language, consent forms are written at a literacy level that exceeds that of the majority of adult Americans, and prescription instructions pose a lethal threat if misunderstood (Meade 1999, Kaphingst 2004, Schwartzberg et al. 2005). Practices that are insensitive to health literacy create an environment that hinders health promotion efforts and threatens patient safety.

Finding effective ways to improve patients' health literacy skills will result in better health outcomes, more satisfying provider/patient relationships, improved preventive care, and cost savings to the entire health care system. In an effort to raise health care professionals' awareness of low health literacy, the American Medical Association Foundation, along with the American Medical Association, launched a Health Literacy Campaign in 2000. As part of this initiative, the AMA developed the Health Literacy Introductory Kit to disseminate information to physicians about the scope of the health literacy problem, the consequences of inadequate health literacy, and strategies to improve verbal and written communication to patients. A sample of health care professionals was surveyed and some were interviewed in order to evaluate the effectiveness and impact of the kit. The intent of the kit was to reach the change agents in the healthcare community in an effort to create awareness about low health literacy and to promote changes in their practices that would help minimize the problem. The kit consisted of five components includ-

ing a video of interviews with patients describing their problems, a discussion guide, the AMA Council on Scientific Affairs report, fact sheets, and a CME program questionnaire.

## 2. Methodology

The AMA Health Literacy Introductory Kit was produced in June 2000 as a self-study educational program for physicians. The objectives of this educational program were to increase awareness of patient problems that result from low health literacy and to offer techniques that could improve communication, efficiency, and patient safety (Schwartzberg 2004). The goal was to generate specific types of clinical practice changes that could alleviate some of the problems associated with low health literacy. Approximately 18 months later (roughly between November 2001 and February 2002), a sample of 472 health care professionals who had ordered the kit were mailed a survey. This 3-page survey was designed to assess users' evaluations of the kit and consisted of questions regarding the information and materials contained in the kit as well as their use of the kit. Of the 472 individuals who received the written questionnaire, 206 responded. Of these respondents, 32% had not yet used the kit but noted they intended to in the future; consequently a total of 137 respondents had used the kit. A convenience sample of 44 interested respondents was recruited from those survey respondents who indicated a willingness to participate in an in-depth telephone interview. A majority came from health systems and hospitals (41%) or academic settings (25%).

The telephone interviews were structured to explore the actual use and barriers to use of the kit. Interview questions focused on assessing the most useful aspects of the kit, soliciting recommendations for improvements, and identifying beliefs about health literacy. The interview participants were asked to describe communication techniques they use and find effective when working with patients with low health literacy.

Survey respondents were asked whether they had shared the Health Literacy Kit with any other professionals. Respondents indicating that they have shared the kit were then asked to describe with whom they shared the kit, the number of people with whom they shared the kit, and the settings in which they shared the kit. Next, respondents were asked to describe the kind of response the kit elicited in the individuals or groups involved in their programs. Respondents were then asked whether or not they intend to use the kit in the future. Finally, respondents were

asked to indicate what they liked and disliked about the kit, and what barriers, if any, they encountered when using the kit.

Respondents also indicated whether they have used any of the techniques suggested in the kit, and whether they have noticed any improvements as a result of these techniques. Respondents were also asked whether they are using any techniques for better doctor/patient communication that were not mentioned in the kit. Next, respondents were asked whether they have implemented any permanent changes in their office procedures or medical encounters as a result of the Health Literacy Kit. Finally, respondents offered recommendations for enhancing the usefulness of the kit and for creating future health literacy kits.

All questions administered in the telephone interview were open-ended. The telephone interviews were designed to elicit additional information about key points raised in the survey. Interviewees were asked about their use of the kit and how the materials stimulated such widespread interest, discussion, and system change as was reported in the written surveys. Human subjects research approval was received from the Institutional Review Board at the University of Illinois at Chicago for this study.

### 3. Results

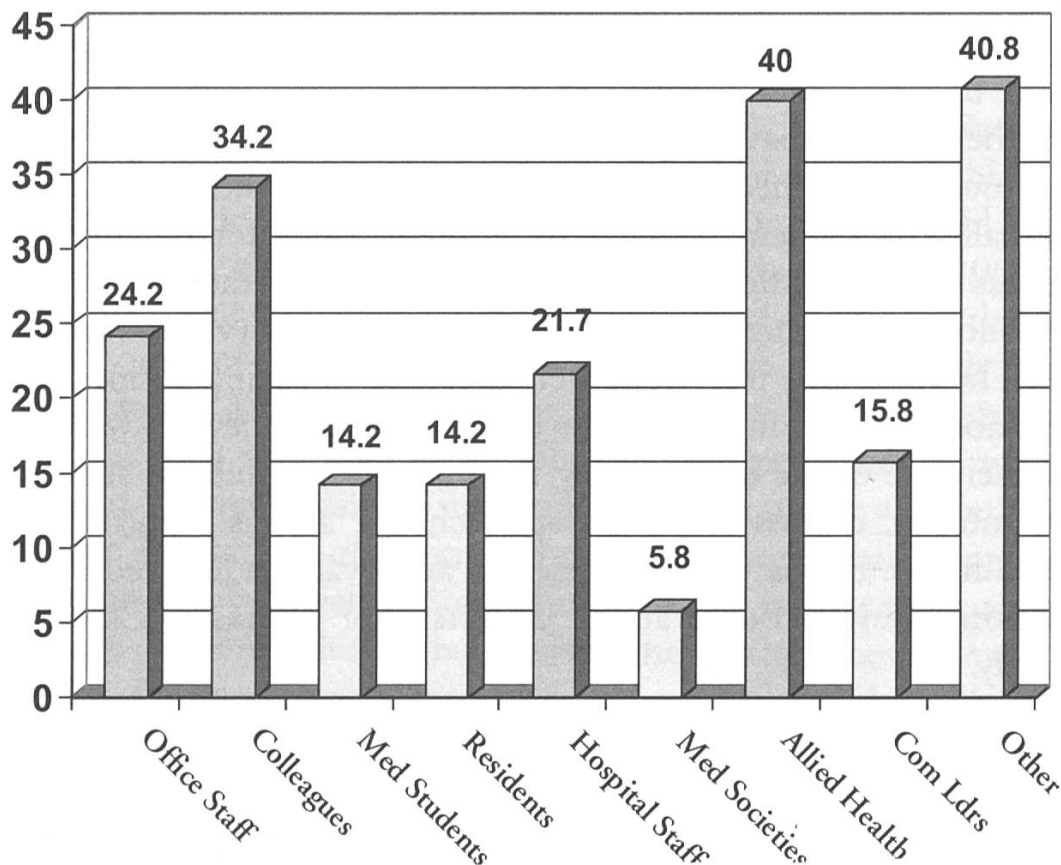
Of the 206 respondents, 137 (67.8%) indicated that they used the kit and 124 (90.5%) of those who used the kit shared that they arranged showings and discussions about the topic. Many used the kit for self-study as well. Of the participants who used the kit and arranged showings, they indicated the showings were with a wide variety of health care professionals, such as allied health professionals (40%), colleagues (34.2%), office staff (24.2%), hospital staff (21.7%), community leaders (15.8%), residents (14.2%), medical students (14.2%), and medical societies (5.8%). (See Figure 1).

The surprisingly wide use of the self-study kit materials to reach out to colleagues and others in the health care system was further investigated through the telephone interviews. Some of the comments were particularly revealing:

"We have to include everyone. And I would say not just the patient/physician, I wouldn't use that as the dyad. ... Whether it's the clerk at the front desk filling out patient history information, we need to create a model of what an ideal system would look like from the minute



the patient walks in the door. Whether it's meeting with the nurse [or] with a diabetic educator, every single person who comes in contact with the patient needs to be part of the educational efforts."



*Figure 1: Arranged Showings and Discussions with respondents who reported using the kit and who used it to arrange showings or discussions (n=124)*

"The problem is diffused through all of the various points of entry and access for patients, and it's literally everyday that you see this."

"I have never had an encounter with a patient where there was not some issue, to some degree, about health and the ability to understand what needed to be understood."

"I think that clinicians, not only physicians, but pharmacists and nurses, sometimes fall into jargon, or may take advantage of their clinical training and not realize that what they are sharing with the patient is above and beyond what the patient can understand."

"It's just something you don't think about! I remember one person even saying to me, 'You know what, I just never thought of there being a literacy problem in health care.'"

The most common settings where the kits were used included staff meetings, in-service training sessions, or other educational/training programs within the respondent's organization, hospital, or clinic. Some respondents indicated that they shared the information through more formal workshops, presentations, and training programs with professionals outside the respondent's immediate department or organization. The larger settings included health departments, community organizations and coalitions, grass roots health organizations, business advisory groups, community councils, and medical center leadership groups, to name a few. The information in the kit was shared with a large number of health care professionals. The total number of individuals with whom the kit was shared by the survey respondents was 9,727 people. Each individual presenter reached an average of over 100 healthcare professionals.

"I think the majority of them were relatively surprised at what they saw. Because you read about it, and you give lip service to the fact that, yes, there is a literacy problem out there, but when you actually see some of the interviews and the interactions, I think it just raises awareness more than just reading about it."

The thing that struck most individuals in discussions following the video...was how in some cases very simple instructions can be misconstrued and how complex we get in our dialogue with the patient and assume that they understand."

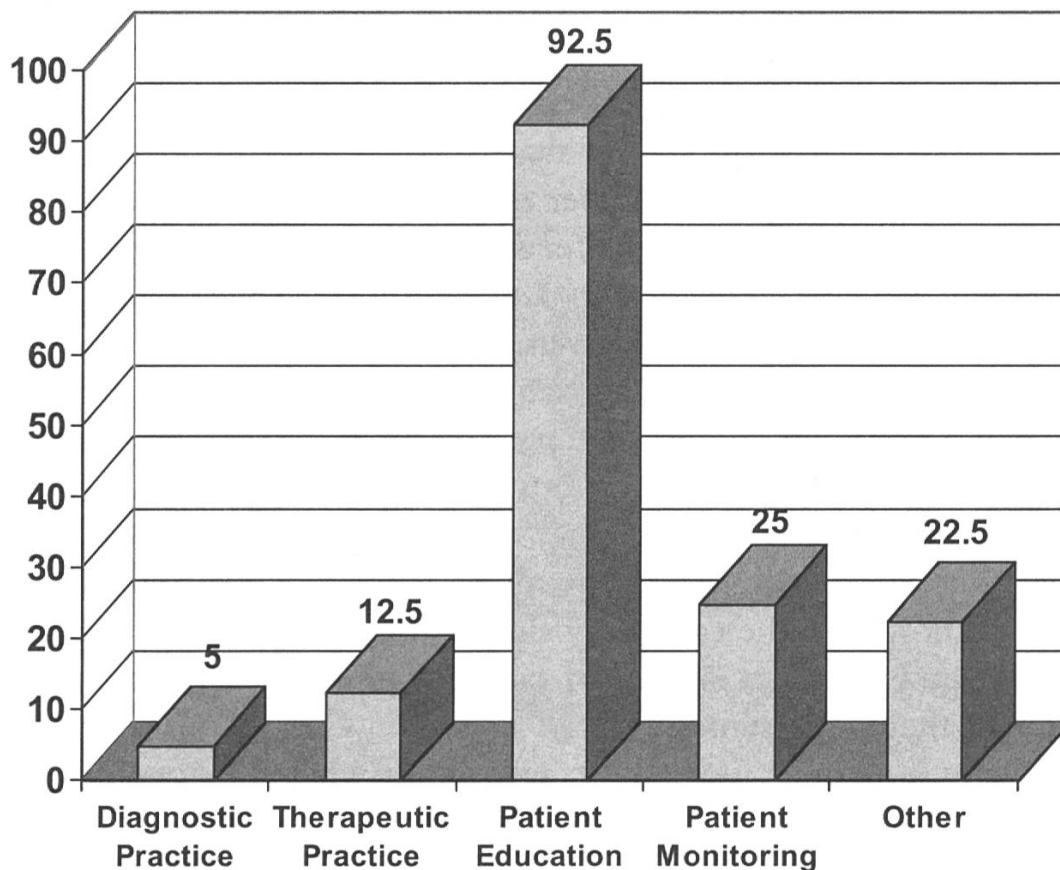
"Virtually everyone...is ready to talk about what they can do [after being exposed to the kit]. ... Our department has taken this on, has really embraced this as an issue to be dealt with all through the clinic. Fourteen months ago, that wasn't true, but everyone in our department has been convinced that this has to be addressed and has gone to champion the cause."

The respondents described items that would improve the usefulness of the kit. They included the following: enhancing the video to model effective communication techniques (89.1%), written information on office-based techniques to assist low literacy patients (84.8%), curricular materials for medical school (65.3%), a manual for faculty teaching about health literacy (77.8%), local seminars and workshops (70.3%), training materials for office staff to create a shame-free environment (84.4%), office practice audits to identify barriers for low literacy patients (59.5%), resources for patient education materials written at easy to read levels (88.8%).

Close to 30% of the total respondents, who were in individual clinical practice, answered questions about changes they made as a result of



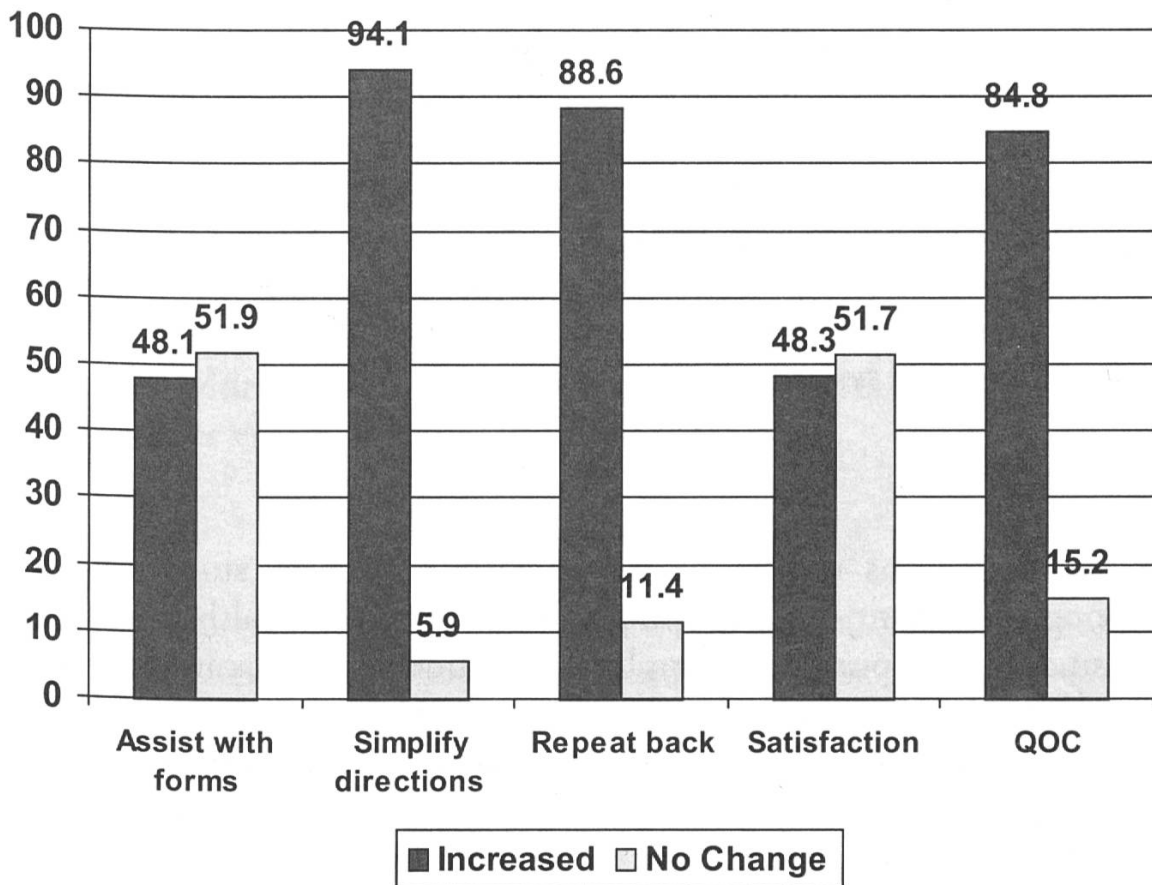
utilizing the kit. Changes were made in the areas of patient education, patient monitoring, and therapeutic and diagnostic practices, although the majority (over 90%) of those who changed clinical practices responded that the changes were in patient education practices (See Figure 2).



*Figure 2: Types of Clinical Practices Changed Respondents who reported using the kit and who changed clinical practices as a result of reviewing the kit (n=40)*

Approximately 88% of the respondents who indicated that they made practice changes reported that they increased their use of the “repeat-back” or “teach back” technique with their patients. Using this technique, the health care professional asks the patient to repeat back in their own words the instructions given by the provider in order to ensure that the patient understands. Approximately 94% of the respondents reported that they simplified directions given to patients in order to improve their health literacy. Several respondents mentioned that they made an effort to avoid using medical jargon and keep verbal communication as simple as possible. 48.3% of respondents said these communication

changes improved their own satisfaction and the quality of care (QOC) that they were providing (See Figure 3).



*Figure 3: Extent Change in Clinician Practice Respondents who reported using the kit and who changed clinical practices as a result of reviewing the kit (n=40)*

#### 4. Discussion

The AMA Health Literacy Introductory Kit initiative was a successful program that accomplished the goals of raising awareness about the low health literacy issue in the United States and producing changes in clinical practices to help alleviate the problem. The most remarkable aspect of the program was its success in encouraging physicians to improve their communication practices with their patients.

Another success of the initiative was the wide dissemination of the kit information to a multitude of health care professionals. Those who requested the kit were inspired to address the problem and thus proactively arranged showings and discussions of the kit materials with their

staff, colleagues, residents, and many others in the health care field. Because of the wide dispersion of information and the practice changes that resulted from the Health Literacy kit initiative, this type of intervention should be utilized for other emerging health issues, such as health disparities or emergency preparedness, for example. It is a low cost, highly effective means of disseminating information and raising awareness about an issue or problem.

Further research is necessary to assess the impacts on patients who were affected by practice changes resulting from the Health Literacy Kit. This would show the impact on the health outcomes of patients, provider/patient relationships, preventive care, and the cost implications to the health care system.

## 5. Limitations

Several limitations should be noted with respect to study findings. Although sufficient for addressing the utility of the health literacy kit, this study used a purposive sample of respondents and it cannot be considered representative of other professionals who may choose to utilize the kit to access and/or improve their interactions with patients who have low health literacy. Participants also had an a priori interest in health literacy that may or may not have influenced their utilization of the kit. While this also makes it difficult to generalize the findings to the larger population of professionals who interact with adult patients, it is unlikely that prior interest in the topic area would significantly influence assessments of the overall utility of the kit given its emphasis on primary education. Additionally, the small sample size does not allow us to examine variation in use/utility across practice area and/or specialty. As a result, we recommend that subsequent research examine how the kit is used in representative samples of professionals as well as explore the use of the kit across the range of allied health care professionals who interact with at-risk populations. Finally, because the data were self-reported, validity must be considered as a concern.

## 6. Conclusions

Physicians are willing to utilize educational interventions to improve care for patients with low health literacy. The AMA developed and distributed its first Health Literacy Kit as part of a comprehensive effort to assist

physicians and other primary health care providers who may be treating at-risk patients. A revised second edition has been released in conjunction with implementation workshops for interested clinicians as well as the publication of the first textbook to explore the implications of low health literacy for medicine and public health (Schwartzberg et al. 2005). As a significant threat to the quality and cost of health care, low health literacy has become a topic of keen interest to policy makers, literacy experts, medical educators, and patients. As clinicians become more aware of its impact, low health literacy has also become an important issue in health services delivery. Educational interventions such as the Health Literacy Kit can assume an important role in motivating practice changes to address this problem, potentially serving as a model intervention for other emerging issues in health care.

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