

## Health Literacy: Improving Quality of Care in Primary Care Settings

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*A 78 year old woman struggles to read the label on her prescription bottle. She knows she needs to take her blood pressure medication, but cannot read the label on the bottle to determine which one is her blood pressure medicine, nor how many she should take, so she picks one. She remembers the doctor told her to take the medicine twice a day so she takes two pills at one time. In an exam room, a 45 year old Hispanic male nods and agrees to what his doctor is telling him in English about diabetes when he came in for knee pain. He leaves unsure of what has happened. His knee still hurts and he doesn't know what diabetes is or why he is discussing it with him. English is not his primary language. In another exam room, a 50 year old Mung patient wonders why the doctor keeps asking her questions about her medical history when all she wants is medicine for her chronic stomach pain. She is not comfortable talking to the doctor and thinks he must not be very good if he has to ask her so many questions.\**

\*The examples above are based on conversations with primary care providers about their patients with low health literacy.

Good patient-clinician communication, where patients are able to understand the health information and treatment recommendations they receive and feel comfortable enough to ask questions or admit when they do not understand something, is vital to the successful management of a chronic illness. However, achieving this ideal level of communication is difficult due to individual and cultural differences in the way patients understand health concepts, view their role in their own health care, and how they view the role of clinicians. Patient-clinician communication is an umbrella under which different facets of the patient-clinician relationship, such as health literacy, culture and communication, rest. Communication, verbal, non-verbal, or written, must be sensitive to patients' language proficiency and reading ability and should be examined within the context of a patient's culture. Understanding the issues of health literacy, culture, and communication and its implications is a lynch pin to improving patient and clinician communication, quality care, and self-management of chronic health conditions.

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## What is Health Literacy?

In the 2004 report by the Institute of Medicine (IOM) entitled *Health Literacy: a Prescription to End Confusion*, health literacy was defined as “the ability to read, understand and act on health information.”<sup>1</sup> Low health literacy can mean not being able to complete office visit and consent-to-treat forms, sign HIPAA documents, or read printed material. Being a health literate individual means that you understand your provider’s recommendations, can take medication correctly, properly use home medical devices, and know where to go and who to seek out when you need help. It means being able to communicate with your care providers to understand your health condition, consider different treatment options, and make informed decisions about the approach to be taken to resolve or manage a health problem. It is the ability to navigate the health care system and feel confident to participate in a dialogue that results in shared decision making. It also means that, as a patient, you are able to understand health information and respond to treatment recommendations made by the clinician, when that clinician accommodates your cultural and linguistic background. For it is culture, made up by beliefs and traditions valued by the patient, that influences the patient’s response to what clinician communicates.

## Who is Affected by Low Health Literacy?

The 2004 IOM report clearly states, “. . . nearly half of all American adults—90 million people—have difficulty understanding and acting upon health information.”<sup>1</sup> According to recently conducted NAALS data, this figure is estimated to be at 77 million individuals due to the establishment of new reporting categories.<sup>2</sup> Although the Agency for Healthcare Research and Quality (AHRQ) documented that low health literacy is predominately an issue for native-born American individuals, low literacy and low health literacy is considered a greater barrier among older adults, people with limited education, the uninsured and those with limited English proficiency.<sup>1</sup> According to Schillinger, people with low health literacy often have more problems managing chronic illness, have higher utilization of health services, and poorer health outcomes.<sup>3</sup>

Until recently, most of the health literacy funding has been within the context of health disparities, resulting in research being directed towards minorities, the uninsured, the underserved, and under-educated—i.e., those generally lacking access to health care and having poor health outcomes. Yet, as we ponder the fact that 77 million American adults have problems understanding and acting upon health information, we realize that we must examine a much more inclusive set of individuals.

Low health literacy is not a problem limited to underserved populations. Both low-literate and well-educated individuals can have difficulty in successfully navigating the health care system. The well-educated and the literate are equally vulnerable and at risk for medical errors and miscommunication as their less educated counterparts if they are not familiar with the health care system or accustomed to

the medical jargon used when discussing health issues. Clear communication, using simple language, is important for all who seek health care services. Assumptions about health literacy levels based on the formal educational level or socio-economic status of a patient can be misleading.

### **Patient-Clinician Communication in the Medical Encounter**

Literature suggests that low health literacy has been considered a better predictor of health status than education, SES, employment, race or gender.<sup>4-5</sup> In its deliberations, the IOM Health Literacy Committee envisioned a health literate America as an achievable goal. The Committee envisioned a society “in which people have skills that they need to obtain, interpret and use health information effectively and within which a wide variety of health systems and institutions take responsibility for providing clear communication and adequate support to facilitate health-promoting action.”<sup>21</sup>

The 21st century has promoted e-technology, more sophisticated medications, and better treatment options; however, society has fallen short on ensuring that all individuals can take advantage of the technological and clinical advancements. Health care service delivery is so focused on disease diagnosis, cost containment, and cost effectiveness that it has forgotten about the human element—the need for interaction and understanding not only to make informed health decisions, but also to manage a chronic illness at home. Given the current model of health care service delivery, primary care clinicians as well as the entire transdisciplinary-care team have limited time to spend with patients. Often patients are not given the opportunity to ask questions they have and clinicians may not adequately explain diagnoses or treatment recommendations. In addition, clinicians are often confronted with patients from different cultural and linguistic backgrounds who may present with multiple chronic conditions. With factors such as culture, language, and complicated health conditions to address, achieving the optimal level of communication between clinician and patient can be very challenging. At the same time, individuals are being pushed to assume ownership of their health condition(s) and are being deluged with issues of personal medical responsibility, accountability, and management of their own care. While many have adjusted to this major paradigm shift in health care, and have taken advantage of the plethora of information available via the Internet, the media; and other print material, others lack the skills to be proactive, do not have the tools to do so or cannot take advantage of the tools available to them because of their inability to understand what is being communicated or the written materials being provided to them.

Both primary care clinicians and patients are overwhelmed by the wealth of good and poor information available through numerous venues. Patients with computer skills have access to a number of sources of health information, thus placing greater demands on the clinician to provide more information, clarify misinformation and misinterpretations as well as offer more options for treatment. Many clinicians and their institutions; however, are not adjusting to or responding to the demands for

information and active patient involvement as quickly as some patients would like. At the other end of the spectrum, there are clinicians who would welcome patient participation, especially given the push toward self-management, but who may not have the ability or resources to respond appropriately.

### **Patient-Clinician Communication and Chronic Care Self Management**

In order to make informed treatment and health care decisions as well as manage their health condition(s), patients not only need good information, but they must be able to understand and process the information presented to them. However, providing information in a manner that diverse patients can understand and act upon is often difficult and time-consuming. Patients living with chronic illnesses are expected to self-manage their condition to prevent complications. They may be given written handouts to help them learn about and manage their asthma or diabetes, or a clinician may explain their condition personally. Management of chronic illnesses such as diabetes, asthma, and hypertension requires sustained behavior changes. These diseases require the determination to make major life changes and knowledge and skills of how to use medical devices as well as skills in numeracy.

Health literacy and communication have been linked to good self-management of chronic illnesses and may improve patient health outcomes.<sup>6</sup> However, many patients hesitate to reveal that they do not fully understand what their clinician is telling them to do. They may feel uncomfortable asking for more of the clinician's time when it is apparent that the clinic is busy; furthermore, it may be inappropriate in some cultures to ask questions of a clinician. It is not uncommon for some patients to disguise their lack of understanding by appearing to agree to what has been said by nodding their head or by making excuses for not being able to read the prescription bottle. These patients often leave the visit confused about what their condition or illness is, what their treatment options and recommendations are, and how to take the medications prescribed. Patient empowerment through information and trust are viewed as fundamental requirements for ownership and successful management of a health condition.<sup>7</sup> Although willing to comply with treatment recommendations, they have no idea how to accomplish this and have less chance of being successful at managing their condition in the home environment. Many times these patients are categorized as being *non-compliant* or of having *low adherence*.

Although useful in health decision-making, health literacy does not guarantee changes in health behavior for all patients. Factors that contribute to successful behavior modification include one's environment, motivation level, and culture, i.e. one behavior that is acceptable in one culture is not acceptable in another. However, regardless of a patient's culture or home environment, good patient-clinician communication is the essential first step to the successful management of a health condition.

## Patient-Clinician Communication in Underserved Populations

Currently, the Association of Clinicians for the Underserved (ACU) is conducting a study of primary care health facilities that serve underserved populations to assess health literacy practices or activities targeted at improving patient-clinician communication, especially for patients challenged with low health literacy. Previously, most studies have been conducted in hospital settings. However, for many underserved populations, the primary care clinician at a community health center is the first point of contact for health care and many of these health facilities lack evidence based tools and sufficient resources to appropriately and effectively communicate health information, and establish realistic self-management plans with patients that can be sustained for the duration of the chronic illness (ACU, 2006).

When an acute medical situation arises, accessing care is a person's first priority. For uninsured or underinsured patients who present in emergency departments, health literacy and communication is not the primary concern. In fact, according to Woolf et al., informed choice is a marginal concern eclipsed by the more pressing priority of gaining access to care.<sup>8</sup> Hence, these patients are less likely to engage in active decision making. These users are limited in knowing their patient rights and the provider expectations and do not challenge the clinician partially due to years of system and self-induced psychosocial barriers. They enter into an environment of asymmetrical relationship building with providers where they often feel the lack of *empowerment* that often accompanies illiteracy. Shared decision making and asking for clarification is lost in victimization conveyed by societal "isms."

### Changes in the System

The Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) health literacy roundtable workgroup has agreed on the need for change in the culture of medicine, creating a shame free environment where treatment questions are welcomed (JCAHO, 2005). A change in the system to create one that encourages the building of patient-clinician relationships and communication has great implications for the quality of care and patient health outcomes.<sup>9</sup> A medical encounter in which a patient feels he or she has the attention, time, and genuine concern of a clinician can improve health outcomes.<sup>9</sup> Improved patient-clinician communication may improve a patient's understanding of his/her disease, improve understanding of treatment plans, increase understanding about prescription drug dosage and usage, and increase patient empowerment and motivation to make behavior changes. However, the current system of care does not encourage sustained interactions, instead pushing clinicians to see as many patients as possible during one day. Furthermore, not all clinicians are also equipped with the training and skills to build relationships with their patients.

Clinicians are grappling with how to reprogram 8–12 years of extensive professional training and use of medical jargon to translate complex medical diagnoses and simplify explanations into basic concepts with clear and simple language so that patients can comprehend their diagnoses, and understand what must to be

done to equip themselves with skills and strategies to own their health and be able to self-manage their care. Some researchers have investigated the effectiveness of decision or health counselors who can educate patients about what the physician has recommended.<sup>8</sup>

Researchers differ about where training and education should be conducted. Clinicians must be trained to communicate with patients and patients must be skilled at asking questions and asking clinicians to explain something they may do understand. It is important to remember, however, that not all patients want to be apart of the decision making process. Many want the clinician to tell them what is best for them and what they need to do to get better. Many patients still believe that the doctor knows best. However, even patients who do not question their clinician's recommendations and do not participate in deciding on their treatment plans must still be able to understand and implement what they are told to do.

Regardless of the numerous journal articles written, and research studies and trainings conducted, a recent study suggests that clinicians may be familiar with the term health literacy, but lack the evidence-based techniques and tools to assess expediently the literacy levels of their patients and plan treatment accordingly (ACU, 2006). Although the majority of clinicians take the view that it is their responsibility to assess the literacy level of their patient, they generally respond to their gut feelings assessing the actual literacy level of the patient and rely on nurses, nurse practitioners, and other members of the clinical team to follow-up with the patient to insure that patients understand the treatment recommendations and instructions for taking medications. This ACU study also found that many health facilities serving underserved, minority populations equated health literacy with having bilingual staff and interpreters (ACU, 2006). Though having staff members who can communicate with a patient in his or her own language is the first step, it is imperative to remember that information translated into a language a patient can understand that does not necessarily mean the patient is able to understand that informational content.

It is important to make sure that interpreters are health literate so that they translate medical information accurately. Inaccuracies can cause a patient serious confusion and frustration. For example, an ACU clinician reports that an interpreter once translated to a patient that he had a liver problem when it was actually his gallbladder that was the problem. The patient, after several visits and several interpreters finally brought his own translator and asked the clinician what exactly was wrong with him. His previous interpreters had been using the term for gallbladder and liver interchangeably and the patient did not know what was wrong with him. Even if the interpreter and patient speak the same language, there is no guarantee that either the patient or interpreter will understand and translate accurately what a clinician is saying.

### ***Tools and Resources Available to Primary Care Providers***

Too few resources exist for clinicians seeking specific guidance on how to address the issues of health literacy in their own work, and organizationally how to integrate

this cross-cutting issue into the operating philosophy, policies, and procedures of their clinics to improve communication and help patients achieve better self-management of a chronic condition. The American Medical Association, pharmaceutical companies such as Pfizer, Inc., other private industry partners, associations, and direct care clinicians are creating tools to improve the clinicians' ability to serve individuals with low health literacy. Clear communication campaigns, assessment tools such as REALM, S-TOFLA, and The Newest Vital Sign are available.<sup>10-12</sup> The Newest Vital Sign, developed with support from Pfizer, is an assessment tool that can be completed in three minutes. It asks the patient to answer questions after reviewing a nutrition label. The questions ask patients to use numeracy and problem solving skills, and parallel many of the same skills patients need for self-management of diabetes, asthma or other chronic illnesses. As informative as New Vital Signs and other assessment tools can be in evaluating a patient's health literacy level, however, the question of how to communicate with patients with low health literacy. Interventions such as Ask Me 3<sup>TM</sup>,<sup>13</sup> the teach back method, and the Motivational Interviewing<sup>14</sup> method are making some improvement, yet evidence-based techniques must be available. Small changes, such as providing paper and pen in each exam room for patients to write questions while they wait for the clinician or to take notes during the encounter, can improve communication and begin to improve the health literacy of the patient. These techniques can improve patient quality and patient safety.

### **Improving Patient-Clinician Communication**

Raising awareness about the implications of low health literacy among clinicians and providing tools and resources to address these issues is important. Health facilities can conduct *Lunch and Learn* sessions where clinicians can get lunch time training on health literacy, culture, and strategies they can use to communicate with patients. More intensive trainings can include cross-training, role playing, and case study discussion. E-mail reminders, bulletin board reminders, and bathroom reminders are all ways health facilities can keep health literacy a priority of their clinicians.

Improving patient-communication involves systemic changes that involve health systems giving clinicians time during medical encounters to interact with the patient in a shame-free environment. It also involves patients being aware of their rights and being equipped with the knowledge that they are allowed to be, and are encouraged to be involved in their health care and it involves clinicians having the skills to communicate and interact with patients. Many medical schools are beginning to realize this need and are modifying their curriculums to include courses that address health literacy and communication techniques with patients (ACU, 2006). Many practicing clinicians are starting to take acting and/or communication classes in order to learn how to effectively interact and communicate with their patients.<sup>15</sup> There is still much work that must be done to ensure patients and clinicians are able to communicate effectively given varying health literacy levels, cultures, and linguistic backgrounds. However, it is encouraging to learn that many primary care health facilities, especially those serving underserved communities are aware of the

problem and are using what resources they have to help patients understand and care for their health condition.

## Notes

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