

“What Did the Doctor Say?:” Improving Health Literacy to Protect Patient Safety



*Another in the series of Health Care
at the Crossroads reports*

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“What Did the Doctor Say?:” Improving Health Literacy to Protect Patient Safety

Joint Commission Public Policy Initiative

This white paper emanates from the Joint Commission's Public Policy Initiative. Launched in 2001, this initiative seeks to address broad issues that have the potential to seriously undermine the provision of safe, high-quality health care and, indeed, the health of the American people. These are issues that demand the attention and engagement of multiple publics if successful resolution is to be achieved.

For each of the identified public policy issues, the Joint Commission already has relevant state-of-the-art standards in place. However, simple application of these standards, and other one-dimensional efforts, will leave this country far short of its health care goals and objectives. Rather, the Joint Commission has devised a public policy action plan that involves the gathering of information and multiple perspectives on the issue; formulation of comprehensive solutions; and assignment of accountabilities for these solutions. The execution of this plan includes the convening of roundtable discussions and national symposia, the issuance of this white paper, and active pursuit of the suggested recommendations.

This paper is a call to action for those who influence, develop or carry out policies that will lead the way to resolution of the issue. This is specifically in furtherance of the Joint Commission's stated mission to improve the safety and quality of health care provided to the public.

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Introduction

“Everything was happening so fast and everybody was so busy,” and that is why Mitch Winston, 66 years-old and suffering from atrial fibrillation, did not ask his doctor to clarify the complex and potentially dangerous medication regimen that had been prescribed for him upon leaving the hospital emergency department.¹ When he returned to the emergency department via ambulance, bleeding internally from an overdose of Coumadin, his doctor was surprised to learn that Mitch had not understood the verbal instructions he had received, and that he had ignored the written instructions and orders for follow-up visits that the doctor had provided.² In fact, these had never been retrieved from Mitch’s wallet.³ Despite their importance, they were useless pieces of paper. Mitch cannot read.⁴

The risk of miscommunication and unsafe care is not solely the potential fate of those who cannot read. It is a risk for a large segment of the American population who, according to the most recent national literacy study, have basic (29 percent) to below basic (14 percent) prose literacy skills.⁵ An additional five percent are non-literate in English.⁶ About half of the U.S. adult population has difficulty using text to accomplish everyday tasks.⁷ The ability of the average American to use numbers is even lower – 33 percent have basic and 22 percent have below basic quantitative skills.⁸ These skills include the ability to solve one-step arithmetic problems (basic) and simple addition (below basic).⁹

When literacy collides with health care, the issue of “health literacy” – defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions¹⁰ – begins to cast a long patient safety shadow.

Most Americans (44 percent) fall into the “intermediate” level of prose literacy. That is, they can apply information from moderately dense text and make simple inferences.¹¹ Yet, health care information – such as insurance forms, consent forms, and medication instructions – is often very complex and seemingly impenetrable. Even those who are most proficient at using text and numbers may be compromised in the understanding of health care information when they are challenged by sickness and feelings of vulnerability.

According to the Institute of Medicine, there is more to health literacy than reading and understanding health information.¹² Health literacy also encompasses the educational, social and cultural factors that influence the expectations and preferences of the individual, and the extent to which those providing health care services can meet those expectations and preferences.¹³ Health care practitioners literally have to understand where their patients “are coming from” – the beliefs, values, and cultural mores and traditions that influence how health care information is shared and received.



Effective communication is a cornerstone of patient safety.

Introduction

The communications breakdown that Mitch Winston experienced happens every day in every place where people seek health care services. It happened to a concerned wife when she consented to have a “percutaneous endoscopic gastrostomy tube” inserted into her husband, not knowing that it was a “feeding tube,” which was against the family’s wishes.¹⁴ It happened to the Hmong-speaking parents of infant Lia Lee, who were unable to describe Lia’s epileptic seizures to the English-speaking emergency department doctor who was treating her, which led to her initial misdiagnosis of pneumonia.¹⁵

Effective communication is a cornerstone of patient safety. The Joint Commission’s accreditation standards underscore the fundamental right and need for patients to receive information – both orally and written – about their care in a way in which they can understand this information. Further, accredited organizations are explicitly encouraged to ensure patient understanding.¹⁶ Indeed, several of the Joint Commission’s National Patient Safety Goals – requirements for accreditation set by an expert patient safety panel – specifically address communication issues. But health literacy issues which go unrecognized and unaddressed undermine the ability of health care organizations to comply with accreditation standards and safety goals meant to protect the safety of patients. The safety of patients cannot be assured without mitigating the negative effects of low health literacy and ineffective communications on patient care.

Addressing health literacy issues is not the sole burden of those providing health care services. There are implications as well for health care policymakers, purchasers and payers, regulatory bodies, and health care consumers themselves. For this reason, the Joint Commission appointed an expert Roundtable panel that comprised a broad range of stakeholders who are accountable for addressing health literacy. The Roundtable was asked to frame the issues that underlie the health literacy problem and propose solutions for their resolution. Among the specific issues addressed by the Roundtable were the impact low health literacy has on patients and their safety; the current state and quality of health care communications and their impacts on all patients; health care provider and public health interventions aimed at improving health care communications; and the need to create organization cultures that place a high priority on culturally competent and safe environments in which clear communications are intrinsic to all care processes and interactions.

This white paper represents the culmination of the Roundtable’s discussions. If actively pursued, the multiple recommendations in this report offer a real opportunity to improve health literacy, reduce communications-related errors, and better support the interests of patients and providers of care alike.



The safety of patients cannot be assured without mitigating the negative effects of low health literacy and ineffective communications on patient care.

Executive Summary

Recommendation I: Make Effective Communications An Organizational Priority to Protect the Safety of Patients

Health literacy issues and ineffective communications place patients at greater risk of preventable adverse events. If a patient does not understand the implications of her or his diagnosis and the importance of prevention and treatment plans, or cannot access health care services because of communications problems, an untoward event may occur. The same is true if the treating physician does not understand the patient or the cultural context within which the patient receives critical information. Cultural, language and communication barriers – together or alone – have great potential to lead to mutual misunderstandings between patients and their health care providers.

Health care organization leaders are responsible for creating and maintaining cultures of quality and safety. Among the key systems for which leaders must provide stewardship for is communications. Yet, awareness of the prevalence of health literacy issues is low among health care executives and other managers.

Health care organizations should know and reflect the communities they serve. This includes not only the primary ethnic groups and languages through which they express themselves, but also the general literacy level of the community as well. The quality of communications and the demographics of the community served become even more important in light of the prevalence of health

literacy problems among specific groups. Those with literacy impairments come from all walks of life; however, educational level, nativity, socio-economic status, and elderly age are all potential indices of low health literacy.

Solutions to Make Effective Communications An Organizational Priority to Protect the Safety of Patients:

- Raise awareness throughout the organization of the impact of health literacy and English proficiency on patient safety.
- Train all staff in the organization to recognize and respond appropriately to patients with literacy and language needs.
- Create patient-centered environments that stress the use of clear communications in all interactions – from the reception desk to discharge planning – with patients.
- Modify strategies for compliance with The Joint Commission’s National Patient Safety Goals to accommodate patients with special literacy and language needs.
- Use well-trained medical interpreters for patients with low English proficiency.
- Provide reimbursement to cover health care organization costs for providing trained interpreters.
- Create organization cultures of safety and quality that value patient-centered communications as an integral component of delivering patient-centered care.
- Assess the organization’s patient safety culture using a valid and reliable assessment tool, such as the AHRQ Hospital Survey on Patient Safety Culture.

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- Assess the organization’s stewardship and acculturation of patient-centered communications, such as through the AMA’s Patient-Centered Communication Framework.
- Become knowledgeable about the literacy levels and language needs represented by the community served.
- Make cultural competence a priority as demonstrated by hiring practices that value diversity and the continuing education of the staff.
- Pursue a research agenda to expand understanding of the impact that communication issues have on patient safety, disparities in health care, and access to care.

Recommendation II: Address Patients’ Communication Needs Across The Continuum of Care

At all points across the continuum of care, low health literacy levels and ineffective communications can compromise patient safety. Recognizing potential symptoms and knowing when to go to the doctor are more challenging for those with low literacy; such individuals are also known to experience poorer health outcomes. Health literacy is an important factor in engaging patients in preventive care as well. Once the need for care is recognized, patients with limited literacy may have difficulty finding their way into and through the health care organization, and be too intimidated to approach others for assistance.

Many patients who have low literacy skills mask what they feel are their inadequacies. For them, there is too much shame in admitting that they do

not read well, or that they do not understand. Physicians, nurses and other health professionals may never know that among the patients they have seen for years, some have suffered silently, grasping far less than others would have expected.

Since a patient’s health literacy skills are typically not evident during a health care encounter, health care professionals need to err on the side of caution and make clear communications and plain language – in the language and at a level that the patient can understand – standard procedure for all patient encounters. This applies to the written materials and verbal information provided in the informed consent process and to patient education.

During a hospital stay, a patient’s care is frequently “handed-off” from one caregiver to the next during shift changes, for special procedures or therapy, or when the patient is transferred to a new unit. Patients may also be transitioned to different care settings rather than being discharged home. All of these scenarios create opportunities for error related to communication breakdowns that must be addressed.

In order to self-manage their own health care, individuals must be able to locate health information, evaluate that information for relevance and credibility, and analyze risks and benefits. For those with limited literacy skills, self-management may be too much of a challenge to be overcome, especially if such challenges are undiscovered or ignored.

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Solutions to Address Patients’ Communication Needs Across the Continuum of Care:

Entry

- Eliminate “barriers to entry” in the care system by educating patients, particularly those with low health literacy, about when to seek care.
- Develop and provide insurance enrollment forms, benefit explanations, and other insurance-related information that is “client-centered,” i.e., written at a low literacy level in plain language.
- Ensure easy access to health care organization services by using clear communications in all wayfinding materials and signage.
- Design public health interventions and communications that are “audience-centered,” including messages that are put in the context of the lives of the target population, and in familiar and preferred formats.

Health Care Encounter

- Apply communications techniques known to enhance understanding among patients:
 - Use plain language always
 - Use “teach back” and “show back” techniques to assess and ensure patient understanding
 - Limit information provided to two or three important points at a time
 - Use drawings, models or devices to demonstrate points
 - Encourage patients to ask questions
- Employ a “universal precautions” approach to all patient encounters by using clear communications and plain language, and probing for understanding.

- Emphasize learning of patient-centered communication skills in all health professional education and training.
- Adopt disease management practices, such as individualized education and multi-disciplinary team outreach to patients, which are known to reduce the incidence of error and positively affect health outcomes.
- Redesign the informed consent process to include forms written in simple sentences and in the language of the patient; use “teach back” during the informed consent discussion; and engage the patient in a dialogue about the nature and scope of the procedure.
- Partner with patients in shared decision-making and provide appropriate education – e.g., through employing patient decision support aids – to inform patient decisions.
- Engage patients in their role as safety advocates by communicating with them about safety and giving them tools to permit their active involvement in safe practices.

Transition

- Standardize the approach to “hand-off” communications:
 - Use clear language so that key information cannot be misinterpreted
 - Use “teach back” and “check back” methods
 - Standardize shift-to-shift and unit-to-unit reporting
 - Smooth transitions to new care settings
 - Give patients information about all of their medications, diagnoses, test results, and plans for follow-up care.

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- Reconcile patient medications at each step along the continuum of care, and provide each patient with a “wallet” card that lists all current medications and dosages, and encourage patients to keep it updated.

Self-Management

- Address the special needs of the chronically ill, many of whom have limited health literacy, so that they are better prepared to self-manage their conditions, such as through modifying and applying the Wagner Chronic Care Model.
- Provide self-management education to patients that is customized to the learning and language needs of the individual patient.
- Regularly place outreach calls to patients to ensure understanding of, and adherence to, the self management regimen.
- Expand patient safety taxonomies to begin to account for and understand patient safety risks associated with self-management.

Recommendation III: Pursue Policy Changes That Promote Improved Practitioner-Patient Communications

If subtle probing in the patient encounter reveals that a patient cannot read, the health care practitioner does have the option of encouraging the patient’s enrollment in adult learning programs. Adult education centers have established track records in raising reading, writing and math skills, but they can also specifically enhance health literacy levels.

Where higher levels of patient intervention and education are required, incentives may be needed to facilitate constructive change in the dynamics of the relationships between patients and physicians. Physicians today are compelled to squeeze more patients into their work day, thus creating the “15-minute office visit.” Patients with limited literacy skills may require more time – time to “teach back,” time to repeat key points in the visit, and time for patient education. Both time and money work against patient education, as this is seldom a reimbursable physician service.

As health insurance premiums continue to rise and significant portions of these costs are shifted to consumers, the pressure on consumers to become well-informed, savvy users of health care services is increasing.

Solutions to Pursue Policy Changes that Promote Improved Practitioner-Patient Communications:

- Refer patients with low literacy to adult learning centers, and assist them with enrollment procedures.
- Encourage partnerships among adult educators, adult learners and health professionals to develop health-related curricula in adult learning programs, and conversely, to assist in the design of patient-centered health care services and interventions.
- Broaden reimbursement policies for patient education provided in physician offices beyond that for diabetes education to other diseases and chronic conditions.

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- Pursue pay-for-performance strategies that provide incentives to foster patient-centered communications and culturally competent care.
- Expand the number of medical liability insurance companies that provide premium discounts to physicians who receive education on patient-centered communications techniques.
- Expand the development of patient-centered educational materials and programs to support the development of informed health care consumers.

Conclusion:

The communications gap between the abilities of ordinary citizens, and especially those with low health literacy or low English proficiency, and the skills required to comprehend typical health care information must be narrowed. Hundreds of studies have revealed that the skills required to understand and use health care-related communications far exceed the abilities of the average person. The high rate of adverse events related to communication breakdowns, now widely recognized, is also widely believed to be unacceptable.

The amelioration of medical error and adverse events must begin with creating cultures of safety and quality. In such cultures, systems and processes of care – from accessing the “system” to the patient encounter, from informed consent to discharge – must be designed to protect the patient’s safety and invite the patient’s participation in his or her care.

Attention especially needs to be paid to the “system” as it is today – the regulatory and reimbursement infrastructure – and the opportunity it provides to effect a chain of changes that will permit patients to receive more time, attention, education and understanding of their conditions and their care.



Health care organization leaders are responsible for creating and maintaining cultures of quality and safety. Among the key systems for which leaders must provide stewardship for is communications.

I. Make Effective Communications An Organizational Priority to Protect the Safety of Patients

Incommunicado

In its 2004 report, *Health Literacy: A Prescription to End Confusion*, the Institute of Medicine (IOM) states that “Although causal relationships between limited health literacy and health outcomes are not yet established, cumulative and consistent findings suggest such a causal connection.”¹⁷

It is well documented that people with low health literacy are hospitalized more often and for longer periods of time,¹⁸ use emergency departments more frequently,¹⁹ and for those with asthma²⁰ or diabetes,²¹ manage their diseases less proficiently.

While there is substantial research linking health literacy and health outcomes,²² far less research has been conducted to identify the precise linkages between health literacy and medical error. Such research is important for purposes of establishing a definitive evidence base, and needs to be pursued. But, despite this need, it is clear that low health literacy and its associated miscommunications and misunderstandings can – and do – increase the risk of adverse events in health care. For even the most health literate, the high literacy demands of health care delivery provide ample opportunity for miscommunication.

If a patient does not understand the implications of her or his diagnosis and prevention or treatment plans, an untoward event may occur. The same is true if the treating physician does not understand the patient or the cultural context within which the patient receives critical information. In fact, communication breakdowns, whether between

care providers or between care providers and their patients, is the primary root cause of the nearly 3,000 sentinel events – unexpected deaths and catastrophic injuries – that have been reported to The Joint Commission.²³ Moreover, communication issues are among the most cited causes underlying medical malpractice litigation.²⁴

Misadventures in the administration of drugs are the most common category of medical error.²⁵ These occurrences arise for a variety of reasons – prescriber error, dispensing error, drug interactions – but they can also be the result of communication problems.²⁶ Indeed, the IOM’s 2006 report, *Preventing Medication Errors*, concludes that current methods for communicating about medications with patients are inadequate and contribute to incidences of medication errors.²⁷ Among its many recommendations, the report underscores the importance of patient-physician communications, and the role of the practitioner in providing definitive education on drug usage.²⁸ The report further recommends that written instructions from pharmacies – on which patients most frequently rely for drug information – must be significantly improved to take into account the literacy, language, age and visual acuity of the individual.²⁹ Another recent study of prescription drug labeling found that while patients with low literacy had particular difficulty understanding medication warning labels, patients at all literacy levels had difficulty understanding multi-step instructions written at the high school reading level.³⁰

Goal Oriented

The Joint Commission’s National Patient Safety Goals were created to prevent sentinel events from occurring. These Goals are based on the recommendations of a group of national patient safety experts that advises The Joint Commission and are regularly updated to address identified areas in health care delivery that present high risks for patient injury. For 2007, 24 setting-specific, Goal-related requirements are in place. Accredited health care organizations are expected to be in compliance with these requirements. The requirements specifically address patient care processes that are known to be vulnerable to error and associated with patient harm.

Limited health literacy and ineffective practitioner/patient communications challenge the ability of health care organizations to meet the National Patient Safety Goal requirements. For instance, Goal 13, which requires that health care organizations encourage patients to be active participants in their care – to be the extra eyes and ears to protect their own safety – is especially challenging for patients with low health literacy. People with low literacy skills or those who speak little or no English often respond passively during care encounters.

Even verbally confirming a patient’s identity – as one of two methods required under Goal 1 which requires accurate patient identification – may be stymied by communications issues. Take the case of Mr. Garcia, who needed to have his staples removed.³¹ When a resident entered his room, he asked the man in bed if he was Mr. Garcia.³² The man smiled and agreeably nodded his head. He then had his staples removed...prematurely.³³ He was not Mr. Garcia.³⁴ Rather, he was a man who did not hear well and who had the habit of smiling and nodding in response to something he did not understand.³⁵ Though, in this case, it was hearing impairment that contributed to the error, it very well could have been a language barrier. Non-English speaking individuals and those with limited English proficiency (LEP) may nod amiably in agreement, without understanding – much less agreeing with – what has been said.

The following table provides a review of National Patient Safety Goals that are particularly relevant to patient-provider communications. The table highlights the obstacles presented by low health literacy and ineffective communications, and provides recommendations for addressing these communications issues.



Limited health literacy and ineffective practitioner/patient communications challenge the ability of health care organizations to meet the National Patient Safety Goal requirements.

Selected NPSGs & Related Requirements	Impact of Limited Health Literacy and Communications Issues on Compliance	Communications-Related Solutions
Goal 1 Improve the accuracy of patient identification.		
<p>1A Use at least two patient identifiers when providing care, treatment or services.</p> <p>1B Prior to the start of any invasive procedure, conduct a final verification process, (such as a “time out,”) to confirm the correct patient, procedure and site, using active—not passive—communication techniques.</p>	<p>Language or communication barriers or patient confusion or mental impairment may impede the patient’s ability to verbally participate in the identification process. A nod of agreement may not be a verification of identification.</p> <p>For procedures done under local anesthesia or when the “time out” is done prior to induction of anesthesia, the patient may be able to participate in the time out. Limited health literacy could compromise the patient’s ability to participate.</p>	<p>Never state the patient name and ask the patient to confirm it. Having a patient state her/his name is safer practice. Having a patient verify her/his identity is appropriate as long as staff consider the patients’ reliability to do so.</p> <p>Site verification and marking should ideally take place with the patient awake, involved and aware if possible. A fail-safe method includes having all of the care team involved, and not starting the procedure until any and all questions and concerns are resolved. The patient’s name, procedure, and the site should be stated aloud, exactly as they appear on the informed consent form, and all team members should actively acknowledge agreement.</p>
Goal 2 Improve the effectiveness of communication among caregivers.		
<p>2A For verbal or telephone orders or for telephonic reporting of critical test results, verify the complete order or test result by having the person receiving the information record and “read-back” the complete order or test result.</p> <p>2B Standardize a list of abbreviations, acronyms, symbols, and dose designations that are not to be used throughout the organization</p> <p>2C Measure and assess, and if appropriate, take action to improve the timeliness of reporting, and the timeliness of receipt by the responsible licensed caregiver, of critical test results and values.</p>	<p>This requirement does not apply directly to caregiver-patient communication, but it is consistent with the process of using “teach back” – asking the patient to repeat back or teach back the information provided to confirm accurate understanding.</p> <p>Adherence to this requirement (2B) is especially important in patient communication since abbreviations, acronyms, and other medical jargon are particularly challenging for all patients, and may be particularly confusing for patients with limited health literacy.</p> <p>Patients with limited health literacy and even adequate literacy may not know the specific tests being performed nor know to, or feel empowered to, follow up on the results.</p>	<p>Caregivers should practice “read back” or “teach back” with their colleagues as well as their patients.</p> <p>When do-not-use abbreviations are discovered, copy the page of the order or medical-related document that contains one or more of the do-not-use abbreviations and send it to the clinician who generated the order or document.</p> <p>Report all critical tests or results to the appropriate responsible licensed caregiver or authorized agent so that the patient can be promptly and properly treated. Provide patients with test orders to take with them to where the test is being done. Inform patients as to how and when they will get test results, and encourage them to follow up and not to assume that “no news is good news.”</p>

Selected NPSGs & Related Requirements	Impact of Limited Health Literacy and Communications Issues on Compliance	Communications-Related Solutions
<p>2E Implement a standardized approach to “hand off” communications, including an opportunity to ask and respond to questions.</p>	<p>Hand offs to patients occur in every patient encounter – to take medications, to encourage active prevention practices, and to manage chronic illnesses – and at discharge from a health care setting. For patients with limited health literacy, hand-offs can be particularly perilous.</p>	<p>Use clear language in communications between caregivers and with the patient. Incorporate effective communications techniques, such as “teach back” or “repeat back,” and limit interruptions. If a patient has limited English proficiency, enlist the services of a qualified medical interpreter. Encourage interactive questioning, and keep the communication patient-centered, and avoid irrelevant details. Smooth hand-offs between care settings. On discharge, provide the patient with information about discharge medications, diagnoses and results of procedures and tests in written and verbal language that the patient can understand. A simple follow-up call to the patient by a doctor, nurse or pharmacist can prevent post-discharge errors. Use technology that can effectively transmit information across care settings and providers.</p>
<p>Goal 3 Improve the safety of using medications.</p>		
<p>3B Standardize and limit the number of drug concentrations used by the organization.</p> <p>3C Identify and, at a minimum, annually review a list of look-alike/sound-alike drugs used by the organization, and take action to prevent errors involving the interchange of these drugs.</p> <p>3D Label all medications, medication containers (for example, syringes, medicine cups, basins), or other solutions on and off the sterile field.</p>	<p>Patients need to be aware of the possibility of drug confusion. This is especially difficult for low health literacy patients</p>	<p>Provide both the brand and generic drug names on the medication label and in the patient’s chart. Explain to the patient the purpose of the medication and, if possible, what the pill will look like.</p>
<p>Goal 7 Reduce the risk of health care-associated infections.</p>		
<p>7A Comply with current Centers for Disease Control and Prevention (CDC) hand hygiene guidelines.</p> <p>7B Manage as sentinel events all identified cases of unanticipated death or major permanent loss of function associated with a health care-associated infection.</p>	<p>Patients with low health literacy may be unaware of common infection transmission modes, and/or do not feel empowered to raise concerns about hand hygiene with caregivers.</p>	<p>Encourage patients and families to speak up and ask health care workers to clean their hands, and remind them to wear gloves.</p> <p>As part of patient education, organizations should teach effective hand hygiene practices.</p>

Selected NPSGs & Related Requirements	Impact of Limited Health Literacy and Communications Issues on Compliance	Communications-Related Solutions
Goal 8 Accurately and completely reconcile medications across the continuum of care.		
<p>8A There is a process for comparing the patient’s current medications with those ordered for the patient while under the care of the organization.</p> <p>8B A complete list of the patient’s medications is communicated to the next provider of service when a patient is referred or transferred to another setting, service, practitioner or level of care within or outside the organization. The complete list of medications is also provided to the patient on discharge from the facility.</p>	<p>The first step in the process is to gather a complete list of the patient’s current medications. It may be more difficult for a low health literacy or LEP patient to provide this information.</p> <p>People with limited literacy are at high risk for medication mix-ups and dosage errors. The elderly, who typically take several drugs daily are most likely to have limited health literacy and decreased cognitive function, and are at particular risk. People at all literacy levels are negatively affected by inadequate drug labeling and preventable medication interactions.</p>	<p>Elicit from the patient as comprehensive a medication history as possible. Consult the responsible pharmacist(s) to fill in gaps or to compile the list, especially when the patient takes 10 or more drugs.</p> <p>Improve the interviewing process with patients by prompting patients with open-ended, specific questions about their health as well as their medications. Be sure to ask if the patient uses over-the-counter drugs, herbals, and/or dietary supplements.</p> <p>After reconciliation, the organization should provide the patient with a medication card that includes the list of all the medications he/she are taking and encourage timely updating of the list. The patient should be encouraged to carry the card in his/her heir wallet or purse.</p> <p>Educate the community (for example, through primary care physicians) so that patients know to bring their medication lists as well as insurance cards when entering a health care organization for admission.</p>
Goal 9 Reduce the risk of patient harm resulting from falls.		
<p>9B Implement a fall reduction program including an evaluation of the effectiveness of the program.</p>	<p>An individual with limited health literacy may have less understanding of the full risks associated with her/his condition.</p>	<p>Communicate a patient’s fall risk to the patient and family and remind the patient to call for assistance before getting out of bed or up from a chair (reassure the patient that this does not bother the staff.)</p> <p>Ask the patient to “show back” or provide a “return demonstration” on how to use the call light button to call for assistance to ensure her/his understanding.</p> <p>Be aware that some patients are prone to falls because of changes in levels of independence, slow adaptation to environmental changes, short-term memory changes, sensory changes (for example visual or auditory), or communication difficulties.</p> <p>Optimize the environment of care by assuring that the patient’s needed objects are accessible at all times, improving lighting, controlling noise, moving higher-risk patients closer to the nurses’ station, eliminating slippery floors or loose carpeting, and installing handrails.</p>

Selected NPSGs & Related Requirements	Impact of Limited Health Literacy and Communications Issues on Compliance	Communications-Related Solutions
Goal 10 Reduce the risk of influenza and pneumococcal disease in institutionalized older adults.		
<p>10A Develop and implement a protocol for administration and documentation of the flu vaccine.</p> <p>10B Develop and implement a protocol for administration and documentation of the pneumococcus vaccine.</p> <p>10C Develop and implement a protocol to identify new cases of influenza and to manage an outbreak.</p>	<p>The elderly, who are high priority for receiving these vaccines, are also most likely to have low health literacy and impaired cognitive function. People with limited health literacy often do not understand when it is appropriate to seek medical attention and to take active steps to prevent illness.</p>	<p>The first step is to consider preventive measures. In ambulatory settings, remind health care providers to offer both flu and pneumococcus vaccines to older patients.</p> <p>Speak slowly, avoid jargon and use “teach back” to ensure the benefits of the vaccines are understood.</p> <p>If the patient cannot remember whether he or she has already received the vaccine, administer the vaccine again. (The CDC has found this to be a safe practice.)</p>
Goal 13 Encourage patients’ active involvement in their own care as a patient safety strategy.		
<p>13A Define and communicate the means for patients and their families to report concerns about safety and encourage them to do so.</p>	<p>People with limited health literacy are more likely to be passive about their care and treatment plans. Those with limited English proficiency may be inhibited from asking questions because of language and cultural barriers. All patients should be encouraged to be active participants in their care.</p>	<p>Explain to patients and their families that the single most important way they can help health care providers to prevent errors is to be active members of the health care team.</p> <p>Use “teach back” to ensure patient understanding at every step of the care process or encounter.</p> <p>Provide explicit – and understandable – information to patients and their families about the risks associated with the health care procedures or courses of care and what to watch out for during or after such care.</p> <p>Provide information – that is patient-centered, reading level or language appropriate, or in diagram form – about potential side effects of treatment so the patient is better prepared if known side effects do occur or if something unexpected happens. Encourage the patient to report a problem right away so he/she can get help before it gets worse.</p> <p>Encourage patients and their families to feel comfortable enough to speak up about any concerns they have about errors or the quality of care they are receiving.</p> <p>Acknowledge generational and cultural factors that may prevent a patient from wishing to be actively involved in patient care decisions.</p>

Selected NPSGs & Related Requirements	Impact of Limited Health Literacy and Communications Issues on Compliance	Communications-Related Solutions
Goal 15 The organization identifies safety risks inherent in its patient population.		
<p>15A The organization identifies patients at risk for suicide.</p> <p>15B The organization identifies risks associated with long-term oxygen therapy such as home fires.</p>	<p>The conduct of a risk assessment requires effective communication between the patient and the clinician.</p> <p>Death or major injury from fire in the home while receiving supplemental oxygen therapy is the most frequently reported sentinel event in the home care setting. Inability to understand the risks associated with smoking when oxygen therapy is being provided or to understand the conditions that can lead to a fire significantly increase this risk for low health literacy or LEP patients.</p>	<p>Employ patient-centered, individualized and empathetic communications with the patient.</p> <p>Provide access to information and communication opportunities, such as through a crisis prevention hotline, for patients and families.</p> <p>Provide education to the patient and family regarding causes of fire and fire prevention activities.</p> <p>Conduct a home safety risk assessment that addresses the presence or absence and working order of smoke detectors, fire extinguishers and fire safety plans, and review all medical equipment.</p> <p>Assess the patient’s level of comprehension and compliance and report any concerns to the patient’s physician.</p>

The numbering of National Patient Safety Goals is not sequential as some goals have been retired and others have been added. Certain goals, such as Goal 11: Reduce the Risk of Surgical Fires in ambulatory care settings, Goal 12: Implementation of the National Patient Safety Goals and Associated Requirements By Components and Practitioner Sites, and Goal 14: Prevent Health Care-Associated Pressure Ulcers were not included in this table because there is not a clear link to patient communications. Solutions for meeting the needs of patients, particularly for low health literacy or low English proficiency patients were derived from the Joint Commission Resources publications: Patient Safety Essentials for Health Care and Patients as Partners: How to Involve Patients and Families in Their Own Care, as well as the Joint Commission’s Speak Up campaign. These are suggestions and do not necessarily represent compliance requirements.

Worlds Apart

In her book, *The Spirit Catches You and You Fall Down*, Anne Fadiman describes the several-year-long medical plight of young Lia Lee, her parents, and the American medical professionals who treated her. Twice, Lia Lee, a few months-old and suffering epileptic seizures, was brought to the emergency department (ED) of the community hospital in Merced, California, where her refugee Hmong parents had resettled the family. Twice, Lia was misdiagnosed with pneumonia because of the

inability of her Hmong-speaking parents and the English-speaking physicians to communicate with each another. At each discharge, Lia’s father signed consent forms he could not read and discharge instructions he neither read nor understood.

When Lia’s condition worsened and she was eventually correctly diagnosed, she was prescribed a remarkably complex pharmaceutical regimen that included look-alike drugs, the labels of which her parents could not read. Her parents were also

required to fractionate pills, administer liquids through droppers, and gauge her temperature – the measures and markers for which they could neither figure nor read.

Through her young life, neither Lia’s parents nor her medical team ever fully understood each other’s perspectives on Lia’s illness. The physicians and nurses who treated Lia conveyed extreme frustration with what they perceived as Lia’s “non-compliant” parents and their inability to prevent Lia’s eventual grand mal seizure. Lia’s parents were equally frustrated because their cultural beliefs and traditional healing methods were not recognized and respected by the care team. As a result, mistrust, intolerance, and a host of errors contributed to – at the close of Fadiman’s book – a tragic outcome for Lia.

Lia’s story has become an oft-noted cautionary tale of cultural and communication barriers, and the negative outcome that may result from misunderstandings between caregivers and patients and their families.

L.E.P. in the U.S.A.

Approximately 21 million people in the U.S. speak English “less than very well.”³⁶ And, there will be significantly more in the years to come. People with limited English proficiency (LEP) can be highly literate in their own languages, but given the immigrant profile of many in the U.S., a number may be, like Lia Lee’s parents,³⁷ unable to read or write in their native languages. Western methods of measurement – such as using a thermometer – and concepts of risk may be completely unfamiliar to some, as they were to the Lee family. In a growing number of communities across the nation,

language barriers – and the accompanying potential for miscommunication – are a priority concern in health care delivery.

A research study conducted by The Joint Commission sought to determine just what happens to LEP patients in U.S. hospitals. The study examined the characteristics – impact, type and causes – of adverse events experienced by LEP and English-speaking patients.

Among the important findings of the study were the differences in impact adverse events had on the LEP versus the English-speaking patients. Some degree of physical harm occurred to 49.2 percent of the LEP patients that had reported adverse events, but only 29.5 percent of English speakers suffered physical harm from adverse events. Further, among those that did suffer harm, 47 percent of LEP patients had moderate temporary harm or worse, compared to only 25 percent of English-speaking patients. The rate at which LEP patients suffered permanent or severe harm or death was 3.7 percent, compared to 1.4 percent of English-speaking patients.

The study does not explain the root cause for these differences. It may be that the English-speaking patients, though vulnerable to preventable adverse occurrences, have more opportunity to participate in their care, communicate expectations and respond to new information, and to understand when transgressions or variations occur. In other words, they are better armed to protect themselves.

Of course, the goal is to prevent errors and harm that could occur because of language issues. Since Lia Lee’s experience in the 1980s, health care

organizations and practitioners are increasingly relying on interpreters in care encounters. However, the only interpreters available are often family members or others who work in the care setting and have some degree of familiarity with the language at hand. This can place both the patient and the physician or other caregiver in a perilous position. In a recent essay in *Health Affairs*, Alice Chen wrote of the challenges and frustration she experienced when she had to rely on her patient's husband as the interpreter.³⁸ Dr. Chen, concerned that her patient's aches and pains and evident depression were the result of spousal abuse, was unable to ask such a question with the husband serving as interpreter.³⁹ Instead, she had to work her way through other possibilities for her patient's condition, without asking what would have been among her first questions.⁴⁰

Title VI of the federal Civil Rights Act requires that hospitals provide interpretation services to LEP patients and those with disabilities that affect their ability to communicate. This has long been an un-enforced mandate, but now the Centers for Medicare and Medicaid (CMS) has initiated a requirement that all of its beneficiaries have access to interpreters. In addition, several states require that hospitals have formal Language Assistance Programs, and others, such as New Jersey and California, have specifically banned the use of children as interpreters.⁴¹ The reliability of interpreters, however, merits much scrutiny, since poorly trained or untrained interpreters can profoundly contribute to, rather than prevent, medical errors and adverse events.

A 2003 study of the rate of errors in medical interpretation conducted by Flores *et al* found that errors

are common and have potentially significant clinical consequences.⁴² The study examined 13 pediatric care encounters that involved hospital interpreters, as well as ad hoc interpreters.⁴³ Ad hoc interpreters included nurses, social workers, and an 11 year-old sibling.⁴⁴ Each encounter, on average, resulted in 31 interpreter errors.⁴⁵ The most common error type was omission (52%), followed by false fluency (16%), substitution (13%), editorializing (10%), and addition (8%).⁴⁶ Sixty-three percent of all errors had potential clinical consequences.⁴⁷ These errors were more likely to be committed by ad hoc interpreters (77%) than by hospital interpreters (53%). The errors included omitting questions about drug allergies; omitting instructions on the dose, frequency, and duration of antibiotics and rehydration fluids; adding that hydrocortisone cream must be applied to the entire body, instead of only to the facial rash; instructing a mother not to answer personal questions; omitting a statement that a child had already been swabbed for a stool culture; and instructing a mother to put amoxicillin in both ears for treatment of otitis media.⁴⁸

Flores *et al* conclude that third-party payers should consider reimbursing health care providers for their use of trained interpreters to discourage the use of ad hoc interpreters and mitigate the resulting high rate of errors.⁴⁹ Indeed, according to a recent study by the Health Research and Educational Trust, only three percent of hospitals receive reimbursement for interpretation services, yet 80 percent of hospitals treat LEP patients.⁵⁰ Although the federal government has deemed medical interpreters a reimbursable expense under fee-for-service Medicaid, it is up to states to determine whether they will pay for these services and only eight have done so thus far.⁵¹

Currently, there are no nationally recognized standards for the training of medical interpreters. Therefore, health care organizations are often left to set their own expectations for interpreter competency, or to rely on local or national training organizations. This has resulted in a national pool of medical interpreters who have inconsistent skills and qualifications. At the most basic level, organizations should have some mechanism for evaluating an individual’s bilingual language proficiency. However, medical interpretation is a skill that requires more than language proficiency. Professional medical interpretation training programs should have curricula that include a basic clinical orientation that addresses anatomy and common illnesses and procedures; interpreter skills, such as managing communication flow; general language and medical terminology; legal and ethical issues; reading comprehension; and cultural competence training.⁵² Guidance on setting performance and training expectations for medical interpreters is available from the National Council on Interpreting in Healthcare, www.ncihc.org.

It may not be practical or economically feasible to always have in-person interpretation, given the range of languages and dialects that are represented in many communities. For languages other than those primarily spoken in the community, many health care organizations rely on interpreter telephone services, often called “language lines.” As with in-person interpretation, the skills and training of the phone interpreters deserves careful scrutiny. Staff should also be trained on whom and how to call for language line services. Any devices needed to facilitate telephonic interpretation, such as hands-free headsets and dual hand-set telephones, should be readily available.

Culture Clash

Language barriers are not the only obstacle to health literacy and effective communication. Culture clashes can erode trust between caregivers and patients and their families and impede effective communication. When it was explained to Lia’s father that she would likely die within hours of being removed from life-sustaining equipment, his impulse was to grab her and run, which is what he did.⁵³ In Hmong culture, it is deeply offensive and threatening to predict the death of someone.⁵⁴ Similarly, when a Spanish-speaking interpreter was asked to tell a Mexican mother that her child would die overnight and there was no more hope, the interpreter refused because “you never tell a mother in our culture to give up hope.”⁵⁵

To encourage “cultural competency” among health professionals, the Office of Minority Health established the Culturally and Linguistically Appropriate Services (CLAS) Standards. The Joint Commission accreditation standards complement and echo the CLAS standards. Both the CLAS standards and those of The Joint Commission recognize that culturally and linguistically appropriate services are essential to safe, high-quality care. However, existing standards may not be sufficient. To raise the bar further, the Joint Commission, with funding from the California Endowment, is currently studying the extent to which hospitals are providing culturally and linguistically competent care. *Hospitals, Language and Culture* is a three-year project to gather data from a sample of hospitals to assess the challenges they face, and their capacity to address the issues of language and culture that impact the quality and safety of care they provide. The information gained from this study will be used to set realistic expectations for culturally competent care in the future.

Preliminary results from the study reveal that while health professionals truly wish to do right by all of their patients, there is a general lack of awareness of the CLAS standards as well as the relevant Joint Commission standards.⁵⁶ Therefore, compliance with either standard set is inconsistent.⁵⁷ Despite recent regulatory efforts, there is also a lack of awareness of the pitfalls of using family members, even children, as interpreters instead of trained interpreters.⁵⁸

According to the Health Research and Educational Trust, 52 percent of hospitals report that they collect information on patients’ primary language to include in their medical records.⁵⁹ Only 20 percent collect information about patients’ literacy levels.⁶⁰ To raise these rates and to improve care for patients across the continuum of care, The Joint Commission has implemented a new requirement that accredited organizations document the patient’s language and communication needs in the medical record. This requirement emphasizes that language and communication needs are a vital piece of demographic as well as clinical information.

Patient-Centered Places

“Mother states she went to MCMC [Merced Community Medical Center] as scheduled for blood test, but without interpreter was unable to explain reason for being there and could not locate the lab. Is willing to have another appt. rescheduled....Mother states she feels intimidated by MCMC complex but is willing to continue treatment there.” This notation in Lia Lee’s county health department record unwittingly describes what so many who have limited literacy or English proficiency experience. Entering a hospital can be like entering another world. Interpreting navigational signs – even getting past the front desk – can

be too difficult. Creating an environment that welcomes all individuals for the provision of safe, high-quality care is every health care leader’s obligation.

Proposed additions to Joint Commission standards would require the leadership of an accredited organization to maintain a culture of quality and safety. For accredited hospitals, the leaders would be expected to assess the hospital’s safety and quality culture using a valid and reliable evaluation tool, such as the survey instrument developed by the Agency for Healthcare Research and Quality (AHRQ).⁶¹ Introduced in 2006, the AHRQ Hospital Survey on Patient Safety Culture will allow hospitals to compare their patient safety culture survey results with those of other hospitals, and to identify areas for improvement.⁶² New Joint Commission standards further require leaders to define how members of the population served can participate in the management of safety and quality issues within the hospital. Among the key systems critical to safety and quality for which leaders must provide stewardship is communications.

In a recent study of hospital executives’ awareness levels respecting health literacy, 65 percent said they were aware of the link between low health literacy and medical error; however, only 25 percent rated the issue as a priority that needed to be addressed in their organizations.⁶³ Given the prevalence of literacy issues, this gap between perception and what is the more likely reality will need to be narrowed.

Several initiatives are underway to determine best practices in patient-centered communications. These are defined as communication that is respectful of and responsive to a health care user’s needs, beliefs, values and preferences.⁶⁴

The American Medical Association’s (AMA) Ethical Forces Program has developed criteria for health care organizations to use in assessing their performance related to patient-centered communications. Among the areas addressed by this Patient-Centered Communication Framework are organizational commitment – the extent to which leadership, staff and resources are committed to the mission of patient-centered communications; community outreach efforts; workforce composition and training; the engagement of patients, with particular attention to respect for socio-cultural diversity; provision of language assistance services; consideration of health literacy and use of clear communication; and application of quality improvement concepts.⁶⁵ The AMA Ethical Forces Program has also initiated a hospital recognition project to raise awareness of innovative approaches to patient-centered communications and to reward hospitals that are leading the way in these efforts.

One organization recognized by the AMA program is the Iowa Health System (IHS). The IHS Health Literacy Collaborative was launched in 2003 to improve the quality of care provided to all patients and their families by raising awareness of health literacy issues and developing effective strategies for enhancing communications throughout its health system.⁶⁶ To meet the goals of the collaborative, key partnerships were identified that included the New Readers of Iowa – adult learners who advise health system staff on the readability of their materials for people who struggle with reading – as well as patients and families, medical and pharmacy societies, and the department of public health. The scope of the collaborative included inpatient

and outpatient settings, as well as support services, such as transportation, and home health and call centers. In addition to addressing health literacy issues in care delivery, the collaborative piloted improvements in navigational aids.

The IHS project also recreated informed consent forms by adjusting reading levels from collegiate to sixth- and seventh-grade levels, and promoted the Partnership for Clear Health Communication’s *Ask Me 3* campaign across health delivery settings.⁶⁷ *Ask Me 3* – through posters, brochures and buttons – encourages patients to ask their health care providers these three key questions: What is my main problem? What do I need to do? Why is it important for me to do this?⁶⁸

The Health Literacy Collaborative also utilized the “teach-back” methodology. “Teach back” entails asking the patient to repeat – or teach back – to the treating clinician the important health care information that has been communicated in the health care encounter to assess and ensure the patient’s understanding. The AMA makes a tool kit available that educates health care professionals on the “teach back” method. “Teach back” is also included among the National Quality Forum’s Safe Practices. The AMA tool kit also encourages physicians to speak more slowly with patients and to use plain language. Whenever possible, physicians should show models or actual devices, or draw pictures. Information should be limited to the two or three main things that patients need to know per visit, and be repeated during the visit. Patients should always be made to feel comfortable asking questions in a “shame-free” environment.⁶⁹

The Collaborative’s tactics heavily emphasize staff education and training. Among the lessons learned is that “administrative leadership is key,” and engagement of patients and families is fundamental to successful strategies.⁷⁰ The Collaborative also found that individuals who struggle with literacy are often patients, but they may also be health system staff.⁷¹

Inside and Out

Health care organizations should know the communities they serve – not simply the primary ethnic groups and languages that are represented, but the general literacy level of the community as well. An interactive tool for determining state, county, town, and even subdivision literacy levels is available at www.casas.org/lit/litcode/search.cfm. While this tool currently relies on 1990 U.S. Census data, plans are underway to update the tool once the requested microdata from the 2003 National Assessment of Adult Literacy are available.

In the 2001 Commonwealth Fund Health Care Quality Survey, substantially higher rates of blacks, Hispanics and Asians reported having “communication problems with their physicians” than did white patients. Further, twice as many blacks as whites (16% vs. 9%) reported being treated with disrespect during a health care visit.⁷² Not surprisingly, race concordance between patients and their physicians has a positive effect on communications and patients’ perceptions of the quality of their care.⁷³ In a recent study, physicians in race-concordant encounters spent more time – 2.2 minutes – with their patients, were rated as “more participatory”

and engaging of the patient, and received higher patient satisfaction ratings than physicians in race-discordant medical encounters.⁷⁴

The 2002 IOM report, *Unequal Treatment*, made clear that distinct disparities exist both with respect to access to care and to the quality of health care for racial and ethnic minorities, regardless of their insurance status or ability to pay.⁷⁵ The study of race-concordant medical encounters underscores the importance of increasing diversity among health professionals, as called for by the IOM. However, it also highlights the central role that effective communications can have on engendering trust and building relationships among patients and physicians of different races.⁷⁶

The focus on the quality of communications and racial and ethnic status becomes even more important in light of the prevalence of health literacy issues among specific groups. Those with literacy issues come from all walks of life; however, educational level, nativity, socio-economic status, and elderly age are all potential indices of low health literacy.

Solutions to Make Effective Communications An Organizational Priority to Protect the Safety of Patients:

Tactics	Accountability
<ul style="list-style-type: none"> • Raise awareness throughout the organization of the impact of health literacy and English proficiency on patient safety. 	<ul style="list-style-type: none"> ➔ Administrative and Clinical Leaders, Patient Safety Directors
<ul style="list-style-type: none"> • Train all staff in the organization to recognize and respond appropriately to patients with literacy and language needs. 	<ul style="list-style-type: none"> ➔ Administrative Leaders, Patient Safety Officers, Social Services, In-Service Educators
<ul style="list-style-type: none"> • Create patient-centered environments that stress the use of clear communications in all interactions – from the reception desk to discharge planning – with patients. 	<ul style="list-style-type: none"> ➔ Administrative Leaders, Department Heads, Social Services
<ul style="list-style-type: none"> • Modify strategies for compliance with The Joint Commission’s National Patient Safety Goals to accommodate patients with special literacy and language needs. 	<ul style="list-style-type: none"> ➔ Administrative and Clinical Leaders, Patient Safety Officers
<ul style="list-style-type: none"> • Use well-trained medical interpreters for patients with low English proficiency. 	<ul style="list-style-type: none"> ➔ Administrative Leaders, Department Heads, Social Services
<ul style="list-style-type: none"> • Provide reimbursement to cover health care organization costs for providing trained interpreters. 	<ul style="list-style-type: none"> ➔ CMS, State Medicaid Agencies, Private Payers
<ul style="list-style-type: none"> • Create organization cultures of safety and quality that value patient-centered communications as an integral component of delivering patient-centered care. 	<ul style="list-style-type: none"> ➔ Administrative and Clinical Leaders
<ul style="list-style-type: none"> • Assess the organization’s patient safety culture using a valid and reliable assessment tool, such as the AHRQ Hospital Survey on Patient Safety Culture. 	<ul style="list-style-type: none"> ➔ Administrative and Clinical Leaders

Tactics	Accountability
<ul style="list-style-type: none"> • Assess the organization’s stewardship and acculturation of patient-centered communications, such as through the AMA’s Patient-Centered Communication Framework. • Become knowledgeable about the literacy levels and language needs represented by the community served. • Make cultural competence a priority, as demonstrated by hiring practices that value diversity and the continuing education of the staff. • Pursue a research agenda to expand understanding of the impact that communication issues have on patient safety, disparities in health care, and access to care. 	<ul style="list-style-type: none"> ➔ Administrative and Clinical Leaders, Patient Safety Officer ➔ Administrative and Clinical Leaders, Clinical Staff, Social Services, Patient Advocates ➔ Administrative and Clinical Leaders ➔ Foundations, Health Care Researchers

II. Incorporate Strategies to Address Patients’ Communication Needs Across The Continuum of Care

The Yellow Baby

Jose Cruz, the son of an immigrant mother, was born in this country. At discharge from the hospital, minimal jaundice was observed by the medical team and his mother was told to seek follow-up care at a local community health center. When he was ten-days old, his mother dutifully sought such medical attention for Jose. At that visit, it was decided that Jose would need a lab test to determine whether blood incompatibility was the source of his jaundice. Because Jose was an American citizen, he was eligible for the Medicaid insurance for which his mother was ineligible. But that would take time and patience to acquire, time that neither Jose nor Mrs. Cruz had. The doctor therefore decided to allow the clinic to cover the cost of the lab test. The test showed elevated but not dangerous bilirubin levels. Mrs. Cruz was scheduled to bring Jose back to see the doctor in one week, but was told to bring the baby back at once if his color should become more yellow and he was not feeding well. Five days later, Jose presented “basically D.O.A.” at the clinic’s door.

The doctor’s first thought was that Mrs. Cruz had ignored his instructions to monitor the baby. But she had not. Worried that Jose was becoming sicker, she had brought him back to the clinic just as the doctor had instructed. The clinic, always busy, was especially busy that day. When she expressed her concerns about the baby to the clinic receptionist – through the interpretation services provided by another mother in the waiting room – the receptionist said that the doctor was too busy to

see Jose and that since she had an appointment in a few days anyway, she should bring him back then. Feeling helpless, Mrs. Cruz brought Jose home where she applied a native remedy – a “healing band-aid” – to his abdomen and tried to feed him rice water. When Jose’s cry became very quiet, Mrs. Cruz returned to the clinic with him. This time, she told the receptionist that she thought Jose was dying. This time, the receptionist let her through. Only it was too late.

This sad tale of a mother and her infant son, paraphrased from the story written by Fitzhugh Mullan in *Health Affairs*, is fiction. But could it be true? Has it been true in some ways in some places in this country? The story illustrates the threat that a bureaucratic, insensitive system poses for patient safety, especially for those who cannot forcefully advocate for themselves.

Step One in the Continuum: Entry

The Welcoming

For people with low literacy skills, navigating the health system is a nightmare. Deciphering hospital signage – “cardiac catheterization laboratory and outpatient radiology this way;” completing complex forms; interacting with physicians; following medication instructions; and coping with real or perceived slights from hospital personnel place high demands on those with low literacy skills.⁷⁷ For some, these demands are too high and they simply avoid health care, to the detriment of their health. One woman put it this way: “I’ve had a lot of

illnesses, but I preferred to stay home, until I get better by taking anything I can. Because being asked to fill this out, to fill that out, I feel embarrassed to ask for help, to ask them to fill them out for me. They might get upset or they would say, ‘This lazy lady, she never learned to read,’ that’s how I think.”⁷⁸

For others, it is not a matter of choosing not to go; it is a matter of not understanding *when* to go. The very first step in the continuum of health care is recognizing the need to seek care or to pursue preventive health strategies. Recognizing potential symptoms and knowing when to go to the doctor are more challenging for those with low health literacy, who are also known to experience poorer health outcomes.⁷⁹ People with low health literacy may delay seeking care, and suffer prolonged symptoms. In one study, men who presented for care with late-stage prostate cancer were found to have lower reading levels than those who presented with early-stage cancer.⁸⁰ The study authors suggest that disseminating culturally sensitive educational materials that reflect literacy levels in the community served can raise awareness of prostate cancer and promote early identification of symptoms.⁸¹

Once the need for care is recognized, the barriers to entry into the health system – whether getting the requisite clearance from a private or public payer, or dealing with gatekeepers, such as recep-

tionists and admissions clerks, at the point of entry – can be overwhelming for anyone, but especially for those who are vulnerable.

A major barrier to entry into the health system is obviously lack of insurance. People with low health literacy, who are also more likely to have low income, are at greatest risk of being uninsured.⁸² Those who may be eligible for Medicaid, or whose children may be eligible under the State Children’s Health Insurance Program (SCHIP), may not pursue benefits because the task of applying is too onerous.⁸³ In one study, 100 percent of enrollees with low literacy levels did not understand the rights and responsibilities section of the Medicaid application, compared to 93.7 percent with marginal health literacy, and 17.3 percent with adequate health literacy.⁸⁴ Typical public benefit forms, like other health-related materials, are written at the 10th grade level of understanding and above.⁸⁵ Application forms are usually several pages long, have dense copy and are complicated – more than intimidating enough to turn potential applicants away or confuse them.

To help state governments improve the approachability and readability of their program materials, the Robert Wood Johnson Foundation funded the development of the *Health Literacy Style Manual*.⁸⁶ This style manual provides guidance on how to turn an application for benefits into a “visual



Deciphering hospital signage – “cardiac catheterization laboratory and outpatient radiology this way;” completing complex forms; interacting with physicians; following medication instructions; and coping with real or perceived slights from hospital personnel place high demands on those with low literacy skills.

invitation,” among other tips for improving communications with the intended audience.⁸⁷ The goal of the manual is to improve state program communications by using “client-centered communications” that will elevate the health literacy of the insured population.⁸⁸ In turn, improved health literacy will result in better use of benefits, better outcomes, and reduced costs. For instance, beneficiaries may take more advantage of well-baby care before delivery; take children in for check-ups; and use emergency departments much less often.⁸⁹

The Public Good

Health literacy is a factor in engaging patients in preventive care as well. In fact, improving health literacy is a goal set by *Healthy People 2010*, the federal government’s public health report that lays out the nation’s health objectives for the first decade of the 21st century. Key to achieving this goal – as well as improving the overall health status of the American public – are effective communications and the coordination of such communications, resource allocations and tactics among public health officials, individual practitioners, and health care organizations.

According to the *Healthy People 2010* report, for health communications to be effective, they must be “audience-centered” – that is, the communication activities must reflect audiences’ preferred formats, media and contexts.⁹⁰ This is especially important in reaching diverse racial and ethnic

populations.⁹¹ The concept of “patient-centered communications” is applicable as well to communications meant for broad audiences of potential patients. Putting information – conveyed in plain language – in the context of peoples’ lives, so that they can identify with and apply it, is equally important in a television or radio broadcast as it is in a one-to-one exchange.

In research undertaken at the University of Michigan’s Center for Health Communication Research, researchers tested the effectiveness of public health messages meant to change behavior. The messages that were most effective were those that framed health advice in a personal context for the audience. Where public health campaigns typically target an audience, say African-Americans, the University of Michigan work revealed that tailoring, not targeting, is the more effective strategy. For instance, many African-Americans have little in common – as in the span of difference between Condoleeza Rice and Snoop Dogg, for instance.⁹² An elderly man may not respond to an admonition to stop smoking because he may die from it, but he may respond to a plea to stop when it is linked to something else in his life he highly values, such as being at his grandson’s wedding.

To decipher individual differences, participants were invited to engage in an interactive, Web-based program that elicited personal health and lifestyle information. This information was then used to



Putting information – conveyed in plain language – in the context of peoples’ lives, so that they can identify with and apply it, is equally important in a television or radio broadcast as it is in a one-to-one exchange.

tailor health messages that were responsive to the particular needs of each user. This work has resulted in the development of tailored interactive communications programs that are accessible through publicly placed computer kiosks in support of public health outreach campaigns, such as one for asthma, and others that are tailored to health care, employer, pharmaceutical, and government settings.

Locating the Lab

Once the need for care is recognized, getting through the front door – and down the corridor – should not be an intimidating experience. Front desk staff should receive training to ensure that they understand how to respond if someone does not speak English well or appears to have “left their reading glasses” behind and needs assistance in reading an appointment slip. All staff in the organization should receive appropriate training in how to recognize and respond to people who have a language barrier, or are unable to read or decipher signage.

Wayfinding – the visual and contextual clues to aid a person’s navigation through the organization – should be able to accommodate the directional needs of everyone – from staff to the non-English speaking patient. Universal symbols, such as those used in airports across the globe for wheel chair accommodations, bathrooms and taxis, may have a place in hospitals as well. The Universal Health Care Symbols initiative led by *Hablamos Juntos*, a Robert Wood Johnson Foundation funded project to improve patient-provider communications for Latinos that is based at the University of California-San Francisco, has developed and tested a set of symbols for potential use in hospital signage.⁹³ Twenty-eight symbols covering major clinical departments and services have been developed and are in the public domain and available for use.⁹⁴

Step Two in the Continuum: The Health Care Encounter

Suffering Silently

Why would a 64 year-old man who was clearly interested in getting and being well – thus his repeat appearances at the community clinic – not take his diabetes and heart medications for weeks on end?⁹⁵ His medication regimen and the dire need for it were clearly spelled out for him again and again. He had his wits about him, he was insured, and he was able to obtain his medications at reduced cost. None of the obvious reasons for his “history of non-compliance” were evident. During his third visit, a medical student, who had been caring for him together with the attending physician, was the first to catch on. The answer came after a glimpse at the man’s glucose log. It was a nonsensical mess. The man was illiterate, having left school in the second grade, and was unable to read his pill bottles and name his medications. Despite the fact that he had seen many physicians, nurses and social workers over the years, none had solved the puzzle of his apparent “non-compliance.”⁹⁶

Neither this man nor Mitch Winston, whose story was shared at the beginning of this paper, told the health care professionals treating them that they could not read. Individuals who do not read or do not read well also do not announce this limitation. Many who have low literacy skills mask what they feel are their inadequacies. For them, there is too much shame in admitting that they do not read well, or that they do not understand. Physicians, nurses and other health professionals may never know that among the patients they have seen for years, some have suffered silently, grasping far less than would have been expected.

A major clue to these patients’ underlying literacy problems is their inability to adhere to medication regimens. Low literacy is in fact associated with greater rate of poor medication adherence.⁹⁷ In turn, poor adherence to medication regimens results in substantial worsening of disease, death, and increased health care costs.⁹⁸

Universal Precautions

Since a patient’s health literacy skills are not typically evident during a health care encounter, health care professionals need to err on the side of caution in making clear communications and plain language standard practice in all patient encounters. Such an approach benefits everyone. It may also be necessary to probe for understanding. Utilizing the “teach back” methodology described in an earlier section of this paper and encouraging patients to ask questions are typical effective ways in which to assess understanding.

Many have reported concern about the time burden of utilizing the “teach back” approach. However, anecdotal reports indicate that “teach back” takes about one minute to complete, particularly where the care provider has become proficient in the practice and has fine-tuned her/his technique.⁹⁹ Given the patient safety implications of flawed communications, this is a minute well spent. Using “teach back,” a patient’s use of the drug Coumadin was discovered just before the patient was about to undergo anesthesia with an agent that was incompatible with Coumadin, thus avoiding a potentially fatal interaction.¹⁰⁰ “Teach back” was used to ensure that a Spanish-speaking woman understood that the tubal ligation she was about to undergo was a permanent sterilization technique, which she heretofore, had not understood.¹⁰¹ She promptly left the hospital.¹⁰² A diabetic patient’s dangerously

low glucose levels were discovered just prior to surgery during the “teach back” process when he was found to be too impaired to “teach back.”¹⁰³

Some advocate that patients’ literacy levels be assessed at the beginning of the care encounter, and there are new methods for briefly assessing patients in a less obtrusive fashion than having them fill out a survey. The Newest Vital Sign is a method that asks patients to answer six questions about a nutrition label.¹⁰⁴ One physician, who is also a noted health literacy expert, carries a pill bottle in her pocket and asks new patients to briefly read the label and instructions.¹⁰⁵ Yet, assessing patient literacy levels in care encounters remains controversial. For those who do not read well, taking any sort of reading test in the doctor’s office is demeaning and recalls the negative experiences associated with test-taking in school.¹⁰⁶

Educating the Educated

Many clinicians may be “blind” to the issue of health literacy.¹⁰⁷ Despite the ubiquity of literacy and language issues in this country, many clinicians seem to feel – like the hospital executives in the previously cited study – that this is not a problem that affects their practice. However, there is growing acknowledgement that ineffective communication – such as rushed conversations, reliance on jargon, language discordance, purposeful ambiguity, and cultural insensitivity – are contributing to unsafe, poor quality care and the uncaring management of too many patients.

Since the 1950s, tension has existed in medical education between the teaching of science-based clinical skills and the development of communication skills – the goal of which has historically been to develop the young physician’s competence in

exhibiting compassion.¹⁰⁸ Through the decades, some medical educators have decried the giving over of precious time in the curriculum to the teaching of humanities that could better be used for increasing student knowledge of rapid advances in medical science.¹⁰⁹

If there has been an ebb and flow in the prioritization of physician communication skills over time, the tide is definitely in today. Through rigorous study, strong physician communication skills have been linked to higher physician and patient satisfaction, greater adherence to medical regimens, improved patient psychological outlook regarding disease control, and enhanced physical and mental health status.¹¹⁰ Acknowledging the importance of effective communication in the delivery of care, the United States Medical Licensing Examination (USMLE) now requires medical students, between the third and fourth year of school, to take a clinical skills examination using standardized patients. The objective of the exam is to determine the ability of the student to gather information from patients, perform a physical exam, and communicate their findings to patients and colleagues.¹¹¹ Communication skills are also an expected competency of medical residents under the standards of the Accreditation Council for Graduate Medical Education (ACGME) and a key component of the Maintenance of Certification model developed by the American Board of Medical Specialties (ABMS).¹¹²

Professional and regulatory standards reinforce the prioritization of communication skills, though they alone do not define and foster the elements that comprise effective communication. Today, the extent to which communication skills are taught – and how those skills are assessed – is highly variable across U.S. medical schools.¹¹³ The tension

that was evident in medical education in the 1950s, and through subsequent decades, persists.

In a recent survey conducted by the American Medical Students Association, one-quarter of medical student respondents said that they had not received any education on health disparities, and more than one-third were not required to study medical ethics.¹¹⁴

Indeed, concern over the growing gap between contemporary patient needs, and the ability of health professional schools to prepare the health care workforce to meet those needs led to the release of another important IOM report, *Health Professions Education: A Bridge to Quality* – the third report in its Quality Chasm series addressing health care quality and safety. In this report, the IOM called for the incorporation of five core competencies into the education of all health professionals. The IOM’s vision is that “all health professionals should be educated to deliver 1) patient-centered care 2) as members of an interdisciplinary team, 3) emphasizing evidence-based practice, 4) quality improvement approaches, and 5) informatics.”¹¹⁵

Patient-centered communication is the linchpin of patient-centered care. Care cannot be patient-centered if it does not effectively involve the patient. Patient-centered communication engages the patient and fosters understanding by portraying medical information within the context of the patient’s life – no matter what that context is. Such communication skills need to be incorporated into all health professional education and training. Conversely, communication that is not patient-centered serves to exacerbate low health literacy and health care disparities. Development

of patient-centered communication skills, including the address of the needs of patients with low health literacy and low English proficiency, needs to be woven into health profession school curricula to a far greater extent than is true today.

Jargon-less

Mrs. Walker – a well composed, articulate woman who reads at the third-grade level – described the dilemma of patients straining to understand the lingo of physicians this way: “Can you imagine what it’s like being sick, and you know that you have limited skills, okay, and you’re talking to an intelligent doctor... And these people are using words that you really don’t know because they’re not speaking in layman’s terms, okay? Most doctors are just presuming that everybody’s as intelligent as they are. And that is just not the case. So . . . you come out of that room, that examination room with this intelligent man or woman thinking: God, I hope I don’t make a mistake with my medicine, because I did not understand anything he or she said to me.”

Mrs. Walker was interviewed for the video, “Health Literacy: Help Your Patients Understand,” that is available from the American Medical Association Foundation. Another patient on the video, when asked by his doctor if he understands what she means when she says he has “hypertension,” answers that she means he is “hyper...when you can’t be still.” This patient had been under treatment for his hypertension for years.

The scientific language of medicine – the lingua franca of physicians – is often a barrier to patient understanding since patients typically have a far less expansive health vocabulary than their care-

givers. Plain language and terms in common usage should be used in place of or to explain medical terminology, e.g. using “high blood pressure” instead of “hypertension;” “fever” instead of “febrile;” “by mouth” instead of “orally.”

Some terminology may even cause misperceptions of illness. The term “congestive heart failure,” commonly called “CHF” by practitioners, may sound to a patient that death is imminent, though it is in fact not a disease but rather a description of clinical syndromes that can be controlled over decades.¹¹⁶ One study suggests that CHF would best be described to the patient as a common chronic condition, and a better term might be “stiff muscle syndrome” or “fluid retention.”¹¹⁷

Each medical discipline has its own jargon that must be translated for patients. One study of health literacy in relation to colorectal cancer screening found that many participants with low health literacy did not know the meaning of commonly used terms, such as “polyp,” “tumor,” “lesion,” or “blood in the stool.”¹¹⁸ None of the participants knew what the colon or bowel was nor where it was located.¹¹⁹

As Mrs. Walker suggests, health care practitioners should speak in layman’s terms whenever possible. After all, the goal of using language is to be understood.¹²⁰

Educational Exchange

The “tyranny of time” – that is reflected by the 15-minute office visit which governs most physician/patient encounters – makes probing for understanding and investing in patient education far from standard practice in the office or clinic

today. Time pressures leave even the most highly literate searching the Internet for answers to questions that they did not have time to ask – or have answered – within their own 15-minute allotment of clinician time.

Several studies have demonstrated the positive effects that applying a disease management approach to patients with chronic conditions and low health literacy can have. In one study, low literacy patients with diabetes who received individualized communication and education, as well as intensive disease management interventions from a multidisciplinary team, were more likely to achieve targeted glucose levels.¹²¹

Better patient education and understanding can also lead to better outcomes, and a better bottom line. In the University of Virginia Health System, eight percent of operating room cancellations were traced to poor patient comprehension of instructions.¹²² Idle operating time results in lost revenue.¹²³ Now, with nurses using “teach back” and placing calls to patients the evening before surgery, the cancellation rate has dropped tenfold.¹²⁴ In addition, the health system uses “teach back” in its informed consent process, and was among the first to have a health literacy curriculum for physicians in training.¹²⁵ For these reasons, the University of Virginia Health System has also been recognized by the AMA’s Ethical Forces program for its patient-centered communication initiatives.

The common problem of medication adherence can also be mitigated through more rigorous patient education, and improving communication between the patient and the physician is known to be an effective strategy.¹²⁶ The physician can elicit the patient’s level of adherence and concerns about

taking medications by acknowledging to the patient the difficulty of taking medications regularly and asking if he or she ever misses taking them.¹²⁷ The physician should also ask whether the patient is experiencing any side effects, if he or she knows why medication was prescribed, and what the benefits of the medication are.¹²⁸ Interventions that include pharmacists, nurses and behavioral specialists can also improve patient adherence.¹²⁹ Patients should be provided simple, clear instructions and the medication regimen should be made as simple as possible.¹³⁰

Uninformed Consent

When Toni Cordell – a well-spoken working woman and mother – consented to her hysterectomy, everything went well. Toni had a good outcome from her surgery. The only problem was that Toni did not know she was having a hysterectomy until after it had occurred. And, she did not learn she had a hysterectomy from her doctor. Several weeks after her surgery, at her post-op check-up, a passing remark from the office nurse tipped her off. At the time, Toni did not read well, and was unable to read the informed consent form she signed. The only verbal explanation given to her by her doctor was that he was going to “give her an easy repair.” Repair, indeed. Luckily for Toni, her child-bearing days were behind her, but the experience left her feeling poorly about herself and the medical system whose care she had sought when she was most vulnerable. Since then, Toni has become an adult learner and literacy advocate who regularly speaks to health care professional groups, including medical students, about the perceptions and needs of those with low literacy skills. Toni often chides physicians and other health professionals to remember that “what is clear to you is clear to you.”

Informed consent forms that are written by lawyers for lawyers do not increase the knowledge of those who, with their signature, are committing to allow the performance of treatments and procedures that may be associated with significant risks. The typical informed consent form is unreadable for any level of reader. Researchers have found that among patients who sign an informed consent form, 44 percent do not know the exact nature of the operation to be performed, and most – 60 to 70 percent – did not read or did not understand the information contained in the form.¹³¹

In order to promote change in the way informed consent is sought, the National Quality Forum (NQF) has developed a guide to help organizations comply with its Safe Practice 10 – one of 28 Safe Practices endorsed by the NQF – which calls for organizations to ensure that patients or legal surrogates understand proposed treatments and their complications. According to the NQF, a safe informed consent process includes asking patients or surrogates to recount what has been told to them during the informed consent discussion; using forms written in simple sentences and in the primary language of the patient; engaging the patient in a dialogue about the nature and scope of the procedure covered by the consent form; providing readers or interpreters to assist patients with low English proficiency, low literacy, or visual or hearing impairments; and conveying the potentially greater risk associated with low-volume providers of high-risk surgeries and procedures.¹³²

For those considering participants in health care research studies, study materials should be easy to read and understand. The Group Health Center for Health Studies in Seattle, Washington has

developed a Readability Toolkit to help research teams improve the quality of study materials. The Toolkit describes strategies for improving readability, including information on how to lower the reading level necessary to understand the study text, offers alternative suggestions for words commonly used by researchers, and provides template language that can be adopted for consent forms.

Decisions, Decisions

Communicating risk is often as challenging for the clinician as understanding risk is for the patient. Physicians receive little training in communicating risk, and, in fact, little is known about the best way to do so.¹³³ The low level of numeracy among patients is an obstacle to comprehending risk that is conveyed in quantitative terms.¹³⁴ The type of information preferred – verbally or numerically described – and how people understand it, is affected by several factors, including the severity of the illness, its potential complications, and patient characteristics such as age, educational level, health status, and recent illness experiences.¹³⁵ Therefore, great flexibility is required in matching information about treatments or care to the needs of individual patients.¹³⁶

Coming to health care decisions that reflect each patient’s preferences and values requires “shared decision-making” – the process by which patients are actively involved with their health care providers in reaching health care decisions.¹³⁷ In the absence of shared decision-making, “interventions are provided to people who would not choose them and withheld from those who would.”¹³⁸

Shared decision-making is a critical element of patient-centered care. Patient-centered care, as called for by the IOM in its *Crossing the Quality Chasm* report, includes customization based on patient needs and values, specifications of the patient as the source of control, shared knowledge and the free flow of information, and evidence-based decision-making.¹³⁹

In order to be partners in making critical decisions regarding their health, patients must be well-informed. To impart the requisite knowledge, a series of patient decision aids – most commonly educational software and multi-media programs – have been developed. These have primarily been focused on common surgical interventions.¹⁴⁰ Testing through clinical trials has found that a number of decision aids improve the ability of patients to make informed decisions; however, these decision aids have largely addressed a limited number of procedure-based medical interventions.¹⁴¹ The application of patient decision aids to the care decisions of the chronically ill remains untested.¹⁴²

Technology-based patient decision aids have not yet been developed specifically for use by patients with limited literacy.¹⁴³ Development of such decision aids should proceed in partnership with the adult education community, as well as with input from adult learners to help ensure the applicability of these tools for narrowing the information gap for these patients.

There are challenges as well to the widespread adoption of decision aids by health care practitioners. Incorporating their use in the care cycle may disrupt the current work flow of physicians and health care organizations and, therefore, require

re-engineering of care processes.¹⁴⁴ Further, since use of patient decision aids has been shown to result in decreased reliance on medical interventions, there may be economic consequences for practitioners and providers that should be addressed, such as through reimbursement for educational counseling services¹⁴⁵ and medical malpractice insurance premium discounts.

It is also important to determine what decision support aids and risk communication approaches work best in achieving effective patient communications. A new initiative of the University of Texas MD Anderson Cancer Center and Baylor College of Medicine, funded by the Agency for Healthcare Research and Quality's Centers for Education and Research on Therapeutics (CERTs), is assessing effective risk communications strategies.¹⁴⁶ Related projects include the development of health decision aids for low literacy populations, as well as computerized health decision aids.¹⁴⁷

Serve and Protect

Patients should be encouraged and educated during the health care counter to participate in decision-making, and also to take steps to protect their own safety. This begins with encouraging their participation in the care delivery process. The more involved a patient is in their care, the less likely an error will occur. However, such involvement may be challenging for patients with low health literacy or low English proficiency, since they often cope by being passive or appearing to be uninterested.¹⁴⁸ Cultural norms also affect how people react during the care process. Indeed, some may choose not to be active participants, and these differences need to be honored.

The Joint Commission encourages organizations to engage patients in their role as safety advocates through the following five steps:¹⁴⁹

1. Communicate with patients about safety. Let patients know that mistakes can and do happen, but that they can help prevent them. Encourage them to ask questions. Be sensitive to cultural beliefs and practices to avoid misunderstandings.
2. Actively involve the patient in safety procedures. Urge patients to become active and informed participants on the health care team. Ask patients to remind staff to identify themselves or to wash their hands. Accredited organizations are required to involve patients in marking the sites for invasive procedures.
3. Give patients safety tools. Provide wallet cards to list medications, allergies, chronic conditions, provider contact information, and so forth. Give patients information on common side effects of medications and procedures and when it is important to call a physician or pharmacist.
4. Be accountable to patients. Make a commitment to be transparent with patients about outcomes, whether good or bad. Approach errors with an intent of full, open disclosure. Invite patients to approach staff with safety concerns and foster a culture of safety in the organization that will permit staff to accept this feedback as an opportunity to learn and improve. Include patients or consumers in the conduct of root cause analyses of sentinel events.

5. Bridge the gap between patients and providers. Train patient representatives (such as ombudsmen, social workers, or other patient advocates) on patient safety issues and publicize their availability to patients and the community. Create a patient and family advisory council.

The public at-large is generally well aware of safety issues in health care. According to a July 2004 Wall Street Journal/Harris Poll, 63 percent of Americans are “extremely concerned” or “very concerned” about hospital-based medication errors, and 55 percent are concerned about hospital-based surgical errors. There is probably much less awareness of the role that patients themselves can play in preventing adverse events. Several years ago, The Joint Commission launched a campaign to encourage patients to “speak-up” to their care providers – to ask care-related questions and to be well-informed about their care. The Speak Up™ campaign provides patients with information and specific questions, in easy-to-read language, that they should ask their caregivers under various circumstances. These include receiving medications, undergoing surgery, and being discharged from the hospital, among others. Similar patient safety tools for patients are available from AHRQ, the National Patient Safety Foundation, the Partnership for Patient Safety, PULSE, and others.

Step Three in the Continuum: Transition

The Bermuda Triangle

Forgotten Do Not Resuscitate (DNR) orders, lost lab results, misinterpreted treatment orders, wrong patient information – the list of potential “fumbles” in patient hand-offs, or care transitions, goes on and on – earning the dubbing of “the Bermuda triangle” of health care delivery.¹⁵⁰ In the course of a hospital stay, a patient’s care is frequently “hand-ed-off” from one caregiver to the next during shift changes, for the performance of invasive or other procedures, or when the patient is transferred from one unit to another. Patients also transition to different care settings, or are discharged home. All of these scenarios create opportunities for error, that relate primarily to communication breakdowns.¹⁵¹ As the patient’s care moves from one doctor or nurse to the next, across hospital units and to other settings of care, the only constant is the patient. Where care transitions create significant vulnerability to patients, it is vital that patients be educated and empowered to protect their own interests.

Because of the prevalence of miscommunication that puts patients at risk during hand-offs, The Joint Commission has established a requirement among its National Patient Safety Goals (2E): “Implement a standardized approach to ‘hand-off’ communications, including an opportunity to ask and respond to questions.” In order to demonstrate compliance with this requirement, The Joint Commission encourages practitioners to use clear language so that key information about a patient cannot be misinterpreted, and to utilize communication techniques, such as “repeat-back” and “check-back” to ensure common understanding.¹⁵² Organizations should also standardize shift-to-shift and unit-to-unit reporting to ensure that the right and right amount

of information is shared.¹⁵³ Hand-offs between settings should also be smoothed to prevent problems.¹⁵⁴ On discharge, the patient should be provided with information about his or her medications, diagnoses, results of procedures and laboratory tests,¹⁵⁵ and plans for follow-up care. A follow-up call to the patient by a doctor, nurse or pharmacist has been shown to effectively prevent post-discharge medical errors from occurring.^{156, 157}

Reconcilable Differences

A 68-year-old man with a history of diabetes and atrial fibrillation maintained on warfarin presented to the emergency department (ED) with fever and mental status changes. A lumbar puncture was attempted three times without success, and empiric treatment for meningitis was started. Further examination revealed an area of cellulitis, and intravenous antibiotic therapy was changed accordingly. At the time of admission, the patient was unable to recite his medication history, and his wife was unclear about his medications or their doses.¹⁵⁸

This case from the Agency for Healthcare Research and Quality’s *Morbidity and Mortality Rounds on the Web* illustrates a common deficit in patients’ knowledge about their medications, especially when they are impaired, and the challenges this poses to the delivery of safe health care. Indeed, more than half of all medication errors occur during transitions in care, such as, like this patient, at the time of admission.¹⁵⁹

Medications, once identified and/or newly prescribed, often do not follow the patient through the care process. In one study, one-third of patients who were discharged from hospital intensive care units had at least one important outpatient medication inadvertently discontinued.¹⁶⁰

Preventing such medication errors from occurring can be accomplished through medication reconciliation – the process of collecting the best medication history possible, verifying the list, and comparing it to orders written at admission, transfer, and discharge.¹⁶¹ Medication reconciliation is especially crucial when patients are unable to provide an accurate medication history or when the history is not available to those who must make treatment decisions.¹⁶²

To promote medication reconciliation to the status of standard practice, The Joint Commission made it a National Patient Safety Goal (requirements 8A and 8B). In addition to requiring communication of a complete and accurate list of medications to caregivers at each step along the patient’s continuum of care, the Goal requires that the patient be given the list upon discharge or transfer to another setting.¹⁶³ In compiling medication information, staff members must, to the extent possible, involve the patient in this process.¹⁶⁴ To improve the interviewing process for obtaining medication information from patients, the Joint Commission encourages staff to prompt patients with open-ended, specific questions about their health as well as their medications – for instance, by reviewing with the patient all of their health conditions and asking what he or she takes for each of these.¹⁶⁵ Patients should also be prompted to share information about use of over-the-counter drugs, herbal remedies and dietary supplements.¹⁶⁶

Step Four in the Continuum: Self Management

A Chronic Problem

More than 90 million Americans live with chronic illnesses.¹⁶⁷ Chronic disease accounts for more than 75 percent of the nation’s \$1.4 trillion in medical care costs, and it is estimated that 75 percent of people with a chronic physical or mental illness have limited health literacy skills.¹⁶⁸ Better management of chronic conditions and prevention of complications – complications that lead, most importantly, to poor health outcomes, as well as increased costs – is a top priority for all health care stakeholders. A key aspect to successful chronic disease management is self management – the ability for patients to understand their conditions and be actively involved in their care regimens.

Self management – according to the IOM – also requires that individuals be able to locate health information, evaluate that information for credibility and quality, and analyze risks and benefits.¹⁶⁹ The chronically ill must also be able to describe their symptoms in ways that can be understood by their caregivers.¹⁷⁰ For those with limited literacy skills, self-management may be too great of a challenge to be overcome, especially if such challenges are undiscovered or ignored. Unfortunately, because patient safety taxonomies and databases do not currently address preventable adverse events that happen to patients when under their own care, the precise relationship between self-management and patient safety is unknown.

What is known is that adequate care is being provided to all chronically ill patients only about half the time.¹⁷¹ This is a problem for which the pursuit of solutions cuts across the entire continuum of health care delivery – the education of practitioners and their actual practice, the oversight framework for practitioners and health care organizations, and health care payment policies and practices. The model for chronic care delivery developed by Dr. Edward Wagner of the Group Health Cooperative of Puget Sound seeks to improve care and health outcomes for the chronically ill. The Wagner Chronic Care Model recognizes that the chronically ill suffer from the physical, psychological and social demands of their illness, and that a primary care *team*, not solely a physician, is needed to best meet these varying demands.¹⁷²

The Wagner Chronic Care Model includes six essential elements: community resources and policies, health care organizations, self-management support, delivery system design, decision support, and clinical information systems.¹⁷³ When each of these interdependent elements are optimized to best serve the chronically ill, the model “envisions an informed, active patient interacting with a prepared, proactive practice team, resulting in high-quality, satisfying encounters and improved outcomes.”¹⁷⁴

In light of the prevalence of health literacy issues among patients with chronic illness, some have foreseen the need to include within the Wagner Chronic Care Model framework, interventions that specifically address the needs of those with limited health literacy.¹⁷⁵ One such intervention – an automated telephone diabetes management system for patients with limited health literacy – has been implemented at San Francisco General Hospital.¹⁷⁶ A key aspect of the telephone system is that it was designed with the active involvement of adult learners and others with limited literacy.¹⁷⁷ If successful chronic care depends on an informed, active patient and an equally proactive practice team, as Wagner suggest, then patient-centered communications – for all patients – is itself an essential element of chronic care management.

To support patients’ self management skills, organizations such as the American Diabetes Association and the American Cancer Society have developed online tools to help patients to better understand their diseases, make treatment decisions, and participate in the management of their health and care.

Solutions to Address Patients’ Communication Needs Across The Continuum of Care:

Tactics	Accountability
<p>Entry</p> <ul style="list-style-type: none"> • Eliminate “barriers to entry” in the care system by educating patients, particularly those with low health literacy, about when to seek care. • Develop and provide insurance enrollment forms, benefit explanations, and other insurance-related information that is “client-centered,” i.e., written at a low literacy level in plain language. • Ensure easy access to health care organization services by using clear communications in all wayfinding materials and signage. • Design public health interventions and communications that are “audience-centered,” including messages that are put in the context of the lives of the target population, and in familiar and preferred formats. 	<ul style="list-style-type: none"> ➔ Medical and Public Health Practitioners ➔ Public and Private Payers, State-based Social Services ➔ Administrative Leaders, Facilities Services ➔ Public Health Professionals, Payers, Disease Management Companies and Advocacy Organizations
<p>Health Care Encounter</p> <ul style="list-style-type: none"> • Apply communications techniques known to enhance understanding among patients: <ul style="list-style-type: none"> -Use plain language always -Use “teach back” and “show back” techniques to assess and ensure patient understanding -Limit information provided to two or three important points at a time -Use drawings, models or devices to demonstrate points -Encourage patients to ask questions • Employ a “universal precautions” approach to all patient encounters by using clear communications and plain language, and probing for understanding. 	<ul style="list-style-type: none"> ➔ Physicians, Nurses, Pharmacists and Other Health Professionals ➔ Physicians, Nurses, Pharmacists and Other Health Professionals

Tactics	Accountability
<ul style="list-style-type: none"> • Emphasize learning of patient-centered communication skills in all health professional education and training. • Adopt disease management practices, such as individualized education and multi-disciplinary team outreach to patients, which are known to reduce the incidence of error and positively affect health outcomes. • Redesign the informed consent process to include forms written in simple sentences and in the language of the patient; use “teach back” during the informed consent discussion; and engage the patient in a dialogue about the nature and scope of the procedure. • Partner with patients in shared decision-making and provide appropriate education – e.g., through employing patient decision support aids – to inform patient decisions. • Engage patients in their role as safety advocates by communicating with patients about safety and giving them tools to permit allow for their active involvement in safe practices. 	<ul style="list-style-type: none"> ➔ Health Professional Schools, Training Programs and Continuing Education; Oversight Bodies ➔ Multi-disciplinary Care Teams, Administrative and Clinical Leadership, Patient Educators, Payers ➔ Administrative and Clinical Leadership, Clinical Staff, Risk Managers, Legal Counsel ➔ Physicians, Nurses, Patient Educators ➔ Administrative and Clinical Leadership, Physicians, Nurses and Patient Educators
<p>Transition</p>	
<ul style="list-style-type: none"> • Standardize the approach to “hand-off” communications: <ul style="list-style-type: none"> -Use clear language so that key information cannot be misinterpreted -Use “teach back” and “check back” methods -Standardize shift-to-shift and unit-to-unit reporting -Smooth transitions to new care settings -Give patients information about all of their medications, diagnoses, test results, and plans for follow-up care. 	<ul style="list-style-type: none"> ➔ Administrative and Clinical Leadership, Clinical staff

Tactics	Accountability
<ul style="list-style-type: none"> Reconcile patient medications at each step along the continuum of care, and provide each patient with a “wallet” card that lists all current medications and dosages, and encourage patients to keep it updated. 	<p>→ Multi-disciplinary Care Team, Discharge Planner</p>
<p>Self Management</p>	
<ul style="list-style-type: none"> Address the special needs of the chronically ill, many of whom have limited health literacy, so that they are better prepared to self-manage their conditions, such as through modifying and applying the Wagner Chronic Care Model. 	<p>→ Multidisciplinary Care Team, Administrative and Clinical Leadership</p>
<ul style="list-style-type: none"> Provide self-management education to patients that is customized to the learning and language needs of the individual patient. 	<p>→ Multi-Disciplinary Care Team, Patient Educator</p>
<ul style="list-style-type: none"> Regularly place outreach calls to patients to ensure understanding of, and adherence to, the self-management regimen. 	<p>→ Multi-Disciplinary Care Team</p>
<ul style="list-style-type: none"> Expand patient safety taxonomies to begin to account for and understand patient safety risks associated with self management. 	<p>→ Health Care Researchers, Patient Safety Experts</p>

III. Pursue Policy Changes That Promote Improved Practitioner-Patient Communications

Reach Out and Read

Recall the 64 year-old man described earlier, who was not taking his diabetes and heart medications, and his doctors discovered that he could not read?¹⁷⁷ With the help of a social worker, he was enrolled in an adult reading program which he attends regularly.¹⁷⁸ His physician reports that after three years, it is not clear that he dutifully takes his medicine as prescribed, but he can now read his pill labels and he feels better able to function in the world.¹⁷⁹

In the patient care encounter, if subtle probing reveals that a patient cannot read, the health care practitioner has the option of encouraging the patient’s enrollment in an adult learning program. Given the established link between literacy and health status,¹⁸⁰ such counseling should be considered as health promotion that is at least as important as smoking cessation, eating well and exercising. And adults with low literacy need more encouragement.

Of course, these services must also be accessible. Federal funding for adult education programs has grown slowly over the years, and presently seven states (California, New York, Massachusetts, Illinois, Michigan, Florida and North Carolina) account for 80 percent of all state funds available for adult learning programs.¹⁸¹

But there is precedent for literacy intervention in the health care encounter. Reach out and Read (ROR) is a program that originated in 1989 at Boston Medical Center through collaboration between pediatricians and early childhood

educators.¹⁸² ROR trains doctors and nurses to advise parents about the importance of reading aloud.¹⁸³ Through the program, books are given to children at their check-up visits from the ages of 6 months to five years.¹⁸⁴ Children growing up in poverty are especially targeted for an ROR intervention.¹⁸⁵ The mission of ROR is to make literacy promotion a standard part of pediatric care so that children grow up with books and a love of reading.¹⁸⁶ When physicians and nurses stress the importance of reading during a health care appointment, that importance is not lost on the parents.¹⁸⁷

Adult education centers effectively elevate reading, writing and math skills, but they can also specifically enhance health literacy levels. Incorporation of health concepts into lessons directed at improving core skills enriches learning and engages students, while providing health information that is relevant to them.¹⁸⁸ The National Center for the Study of Adult Learning and Literacy (NCSALL) is developing curricula and materials for teaching health literacy in adult learning programs in three specific areas: health system navigation, management of chronic disease, and screening and early detection.¹⁸⁹ These are high-priority health care areas for adult learners, who are also health care’s most vulnerable patient population.¹⁹⁰

As exemplified by the Iowa Health System Collaborative, literacy advocates as well as adult learners, can provide valuable counsel to health care practitioners, providers and systems in the design and delivery of health care services that are truly patient-centered.¹⁹¹

Off the Dime

Where more patient intervention and education may be required, it follows that more attention needs to be paid to the incentives to make change happen. In the face of managed care, capitation, public payer reimbursement rates, skyrocketing malpractice premiums, and a host of other financial pressures, physicians are now compelled to squeeze more patients into their work day, thus making the “15-minute office visit” a necessity if not a luxury itself. Within this 15-minute office visit, patients may need to share their health history and current symptoms, undergo an examination, receive an explanation of potential diagnoses, review a therapeutic regimen, and plan for next steps. Patients with low-literacy skills require more time throughout this process – time to “teach back,” time to repeat key points in the visit, etc. This is time well spent as it may help to avoid an error, an adverse event, or an unnecessary hospitalization. However, it is extra time that the physician does not have under current payment models.

Both time and money work against patient education. Patient education is almost always an unreimbursable expense of the doctor’s office. The one exception is for diabetes education. In 1998, CMS expanded its reimbursement policy to cover programs that educate and train diabetics how to self-manage and control their blood glucose levels.

Any physician practice with an American Diabetes Association-recognized certified training program is eligible for such payments.¹⁹² Expanding education reimbursement policy to cover other chronic conditions could help to improve the self-management skills of a broader swath of patients.

Newly implemented pay-for-performance (P4P) programs could provide a real opportunity to reward physicians for providing patient-centered communications, outside of their own professional satisfaction. If patient-centered communications were to a basic pillar of P4P programs across the public and private sectors, that would provide a major boost to aligning improved health care communications with health care payment policy. Measures of performance would need to be determined, but these would logically include outcomes measures such as frequencies of preventable adverse events and hospitalizations, as well as patient satisfaction and relevant process of care measures.

One such program has been implemented by Blue Cross/Blue Shield of Florida. As part of its P4P program, participating physicians are encouraged to improve their performance respecting the delivery of culturally sensitive care. Physicians are given the opportunity to voluntarily participate in an interactive e-learning course called “Quality Interactions.”



Where more patient intervention and education may be required, it follows that more attention needs to be paid to the incentives to make change happen.

This course is designed to help physicians identify cross-cultural issues and perform culturally competent medical exams, identify the impact of culture on medical decision-making, address language barriers, and effectively explain diagnoses and management options to patients.¹⁹³ Physician performance related to cultural competence is then measured through patient satisfaction ratings.

Notwithstanding the opportunities to tie increased attention to health literacy to payment policy, P4P initiatives in this areas area will need to be carefully monitored to assure the avoidance of unintended consequences. For instance, if an improvement objective to reduce average blood glucose levels of diabetic patients in physician practices were established, physicians could be motivated to drop patients from their practices whom they view as “non-adherent” – patients who may be compromised by low health literacy or by cultural barriers to communication.

Patient-centered decision-making could also be folded into P4P programs to create incentives for patients to be provided the care they want and need.¹⁹⁵ In a recent *Health Affairs* article, Sepucha *et al* propose that “documenting gaps in patients’ knowledge and lack of concordance between patients’ values and preferences and the care received could stimulate rapid change, moving

decisions and care closer to the patient-centered ideal advocated by policymakers.”

Health care payers and medical liability insurers should also benefit from the use of patient decision aids and other interventions that support the evolution of well-informed health care consumers. That should be reason enough to provide incentives to providers and practitioners in the form of expanded reimbursement and premium discounts, respectively, for taking the extra time to educate patients and to use technologies to support these efforts where appropriate.

Acknowledging the link between physician communication skills and liability claims, medical liability insurers are investing in communications skills training and considering premium discounts. One such insurer is ProMutual of Massachusetts. The four-month long communications course offered by ProMutual includes online learning modules, video-taped simulated patient sessions, small work groups, and questionnaires that address communication, health care outcomes, risk and liability.¹⁹⁶ The content of the training also includes how to respond to LEP patients.¹⁹⁷ Physicians from academic medical centers have developed and teach some of the course work.¹⁹⁸



Steps need to be taken to help people jump through the hoops of bureaucracy so that they can access benefits and care services. Steps need to be taken to ensure that patients understand their health conditions and how to take their medications safely.

Consumer Conscious

As health insurance premiums continue to rise and significant portions of these costs are shifted to consumers, the pressure on consumers to become well-informed, savvy users of health care services is increasing. But the expectation that consumers at all literacy levels become knowledgeable health care decision-makers creates an obligation on the part of public and private sector payers both to provide, to support financially, and to create incentives for the provision of consumer education that will make this goal achievable.

It is also in the best interests of employers and payers to enhance employee access to requisite services and to eliminate barriers to effective health care delivery. Aetna and Marriott International have launched an initiative to address health care concerns among Marriott employees who had significantly high rates of diabetes, elevated cholesterol values and hypertension.¹⁹⁹ The initiative seeks to address health literacy, language,

and other cultural barriers in health care delivery. Through education and outreach, the goal of the initiative is to reduce health care disparities and optimize communication between Spanish-speaking Marriott employees and their health care practitioners. The initiative is being piloted in Miami and Houston and offers outreach calls and targeted mailings to Marriott members and primary care physicians in those cities. Measures of success for this initiative include improved adherence to medication regimens, and improvements in hospital use, emergency room visits, and enrollment in disease management programs.²⁰⁰

Solutions to Pursue Policy Changes That Promote Improved Practitioner-Patient Communications:

Tactics	Accountability
<ul style="list-style-type: none"> • Refer patients with low literacy to adult learning centers, and assist them with enrollment procedures. 	<ul style="list-style-type: none"> ➔ Physicians, Social Workers
<ul style="list-style-type: none"> • Encourage partnerships among adult educators, adult learners and health professionals to develop health-related curricula in adult learning programs, and conversely, to assist in the design of patient-centered health care services and interventions. 	<ul style="list-style-type: none"> ➔ Adult educators, Adult Learners, Health Professionals
<ul style="list-style-type: none"> • Broaden reimbursement policies for patient education provided in physician offices beyond that for diabetes education to other diseases and chronic conditions. 	<ul style="list-style-type: none"> ➔ CMS, Private Payers
<ul style="list-style-type: none"> • Pursue pay-for-performance strategies that provide incentives to foster patient-centered communications and culturally competent care. 	<ul style="list-style-type: none"> ➔ CMS, Private Payers
<ul style="list-style-type: none"> • Expand the number of medical liability insurance companies that provide premium discounts to physicians who receive education on patient-centered communications techniques. 	<ul style="list-style-type: none"> ➔ Medical Liability Insurers
<ul style="list-style-type: none"> • Expand the development of patient-centered educational materials and programs to support the development of informed health care consumers. 	<ul style="list-style-type: none"> ➔ Public and Private Payers

Conclusion

When Archie Willard, an adult learner and literacy advocate, goes to the doctor’s office and is given forms to fill out or information to read, he “feels a tightening inside.”²⁰¹ And he will not read in front of you.²⁰² For Toni Cordell, being presented with forms and medical information for her to read is like “asking me to climb Mt. Everest.”²⁰³ If there is more than one page, she too will not read in front of you.²⁰⁴ It is likely that almost everyone has been, at some time, put off by densely worded forms, and confused by complex medical regimens, conflicting health care advice, poorly worded instructions, and medical speak that few on the receiving side of health care can understand. Many leave the doctor’s office with questions unspoken and unanswered, either because they do not want to appear unknowledgeable or feel that their questions – perhaps proffered in the chaos that Mitch Winston described – will be unwelcome.

Language barriers and cultural clashes also inhibit effective bilateral communications, leaving both sides of the care equation short-changed of information that is necessary to the provision of safe, high-quality care. Interpreter services are essential and can break down barriers, but care providers still need to grasp where their patients are “coming from.”

The communications gap between the abilities of ordinary citizens, and especially those with low health literacy or low English proficiency, and the skills required to comprehend everyday health care information must be narrowed. Hundreds of studies have revealed that the skills required to understand and use health care-related communications far exceed the abilities of the average person.²⁰⁵ As a result, communications break down, and untoward events occur.

The high rate of medical errors and adverse events related to communication breakdowns, now widely recognized, is also widely acknowledged to be untenable. In the Joint Commission’s sentinel event database, 65 percent of the identified adverse events have been found to have communications failures as the underlying root cause. Some indeterminate number of these have been complicated by low health literacy problems. The precise impact of health literacy and language issues on patient safety needs to be further evaluated with some urgency so that data, rather than anecdotes, can properly illuminate the problem.



The communications gap between the abilities of ordinary citizens, and especially those with low health literacy or low English proficiency, and the skills required to comprehend everyday health care information must be narrowed.

The amelioration of all medical errors begins with creating a culture of safety and quality. In that culture, systems and processes of care – from accessing the “system” to the patient encounter, from informed consent to discharge – must be designed to protect the patient’s safety and invite the patient’s participation in her or his care.

Steps need to be taken to help people jump through the hoops of bureaucracy so that they can access benefits and care services. Steps need to be taken to ensure that patients understand their health conditions and how to take their medications safely. Steps need to be taken to help patients recognize risks to their health and how these can be mitigated. And whenever the opportunity presents itself, steps need to be taken to help the non-reader read.

It is not sufficient to say, “Thou shalt be done.” Attention needs to be paid to modifying the “system” as it is today. This specifically includes the existing regulatory and reimbursement infrastructure, and its potential – with appropriate modifications – to effect a chain of changes that will make it possible for patients to receive more time, more attention, more education and more understanding.

All of health care’s major stakeholders need to know where Toni and Archie are coming from, and so too the many patients who could be harmed as the result of ineffective communications between them and those whom they entrust with their care.

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Glossary of Terms

Audience-centered communications –

Communications that are tailored to meet the literacy and learning needs of targeted segments of the public

Atrial fibrillation – Irregular heart beat

Cellulitis – A skin infection that if severe or left untreated, can be life-threatening

Chronic illness – An illness of long duration and possibly slow progression

Client-centered communications –

Communications that are tailored to meet the literacy and learning needs of health plan enrollees

Colorectal cancer – Cancer of the colon or rectum

Coumadin – A drug that helps prevent clots from forming in the blood

Congestive Heart Failure (CHF) – A condition in which the heart can no longer pump enough blood to rest the body

Diabetes – a disease in which the body does not produce or use adequate levels of insulin

Glucose level – The amount of sugar in the blood

Glucose log – The record kept by people with diabetes to monitor their blood sugar levels

Hypertension – High blood pressure

Hysterectomy – Surgical removal of part or all of the uterus

Intravenous antibiotic therapy – Administration of a liquid, such as a liquid antibiotic, into the vein

Jargon – Specialized language of a trade, profession, or similar group

Lumbar puncture – (Also called a spinal tap) A test to evaluate the fluid surrounding the brain and spinal cord

Meningitis – An infection of the tissues and sometimes the fluid surrounding the brain and spinal cord

Patient-centered communications –

Communications that are tailored to meet the literacy and learning needs of the individual patient

Repeat back – A method to ensure understanding of information being communicated, often used between members of a care-giving team, by asking the receiver of the information to “repeat back” what was said.

Taxonomies – Classification systems

Teach back – A method to ensure understanding of information being communicated, often used between a caregiver and a patient, by asking the receiver of the information to “teach back” the what was said.

Tubal ligation – A surgical procedure in which a woman’s fallopian tubes are blocked, tied, or cut

Show back – A method to ensure understanding of information being communicated, often used between a caregiver and a patient, by asking the receiver of the information to demonstrate, or “show back” what was demonstrated.

Warfarin – The generic version of the drug, Coumadin, which prevents clots from occurring in the blood

Endnotes

- ¹⁻⁴Wachter, Robert M., Shojania, Kaveh G., *Internal Bleeding*, Rugged Land, New York, NY, 2004, pages 242-244
- ⁵⁻⁹2003 National Assessment of Adult Literacy (NAAL), National Center for Education Statistics, U.S. Department of Education
- ¹⁰Institute of Medicine report, *Health Literacy: A Prescription to End Confusion*, National Academies Press, 2004
- ¹¹⁻¹³NAALS
- ¹⁴Joint Commission Resources, *Patients as Partners: How to Involve Patients and Families in Their Own Care*, 2006
- ¹⁵⁻¹⁶Fadiman, Anne, *The Spirit Catches You and You Fall Down*, Farrar, Straus, and Giroux, New York, NY 1997
- ¹⁷IOM report, *Health Literacy*
- ¹⁸Baker DW, Gazmararian JA, et al, “Functional health literacy and the risk of hospital admission among Medicare managed care enrollees,” *American Journal of Public Health*, 2002;92: 1278-1283
- ¹⁹Baker DW, Parker RM, et al, “The health care experience of patients with low literacy, ” *Archive of Family Medicine*, 1996 5:329-334
- ²⁰Williams, Mark V., David W. Baker, Eric G. Honig, et al., Inadequate Literacy Is a Barrier to Asthma Knowledge and Self-Care (PDF file), Chest, Vol. 114 (4), American College of Chest Physicians, 1998.
- ²¹Schillinger D, Grumbach, K, et al, “Association of health literacy with diabetes outcomes,” *JAMA* 2002;288:475-482
- ²²DeWalt, Darren A., Berkman, Nancy D., Sheridan, Stacey, et al, “Literacy and health outcomes: A systematic review of the literature,” *Journal of General Internal Medicine*, 2004; 19, 1228-1239
- ²³Joint Commission Sentinel Event Data, available at www.jcaho.org
- ²⁴Hickson Gerald B., Federspiel, Charles F., Pickert James, “Patients Complaints and Malpractice Risks,” *JAMA*, 2002:2951-3297
- ²⁵⁻²⁹Institute of Medicine, *Preventing Medication Errors: The Quality Chasm Series*, National Academies Press, 2006
- ³⁰Davis, Terry C., Wolf, Michael S., Bass III, Pat f., et al, “Low literacy impairs comprehension of prescription drug warning labels,” *Journal of General Internal Medicine*, 2006;21:847-851
- ³¹⁻³⁵Wachter, Shojania, *Internal Bleeding*
- ³⁶U.S. Census data, www.uscensus.gov
- ³⁷Fadiman
- ³⁸⁻⁴¹Chen, Alice, “Doctoring across the language divide,” *Health Affairs*, Volume 25, No. 3, May-June 2006
- ⁴²⁻⁴⁹Flores, Glenn, Laws, M. Barton, Mayo, Sandra J., et al, “Errors in medical interpretation and their potential clinical consequences,” *Pediatrics*, 111;1 January 2003: 6-14
- ⁵⁰AHA News, October 11, 2006
- ⁵¹Chen
- ⁵²Hablamos Juntos
- ⁵³⁻⁵⁴Fadiman
- ⁵⁵Rosana Scolari speaking at the IOM Health Literacy Roundtable meeting, January 25, 2006

Endnotes

- ⁵⁶⁻⁵⁸Wilson-Stronks, Amy, “Healthcare Language and Culture: What the Joint Commission is Learning” presentation given at the national conference, Health Literacy: The Foundation for Patient Safety, Empowerment and Quality Health Care, June 26-27, 2006
- ⁵⁹HRET
- ⁶⁰HRET
- ⁶¹⁻⁶²AHRQ, www.ahrq.gov/qual/hospculture/overview.html
- ⁶³The California Health Literacy Initiative, *Low Literacy, High Risk: The Hidden Challenge Facing Health Care in California*, October 2003
- ⁶⁴American Medical Association Consensus Report, Improving Communication - Improving Care, 2005
- ⁶⁵www.ama-assn.org
- ⁶⁶⁻⁶⁷Iowa Health System , AMA site visit, learning session 5 materials
- ⁶⁸www.askme3.org
- ⁶⁹AMA Foundation Toolkit
- ⁷⁰⁻⁷¹Iowa Health System
- ⁷²The Commonwealth Fund, “Patient-centered communication, ratings of care, and concordance of patient and physician race,” www.cmwf.org/publications, viewed 9-05
- ⁷³⁻⁷⁴Cooper, Lisa A., Roter, Debra L., “Patient-centered communications, ratings of care, and patient and physician race,” *Annals of Internal Medicine*, December 2003, 139:11.
- ⁷⁵⁻⁷⁶Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, National Academies Press, March 2002
- ⁷⁷⁻⁷⁸Baker, David W., Parker, Ruth M., Williams, Mark V., et al “The health experience of patients with low literacy,” *Archives of Family Medicine*, Vol. 5, June 1996
- ⁷⁹Dewalt, Darren A, Berkman, Nancy D, Sheridan, Stacey, et al, “Literacy and health outcomes: A systematic review of the literature,” *Journal of General Internal Medicine*, 2004;19:1228-39
- ⁸⁰⁻⁸¹Bennett, CL, Ferreira, MR, Davis, TC, et al “Relation between literacy, race, and stage of presentation among low income patients with prostate cancer,” *Journal of Clinical Oncology*, Vol 16, 3101-3104
- ⁸²Commonwealth Fund
- ⁸³The Health Literacy Style Manual, Covering Kids and Families, October 2005
- ⁸⁴Gazmarian, Julie A., David W. Baker, Mark V. Williams, et al., “Health Care Literacy Among Medicare Enrollees in a Managed Care Organization”, *JAMA*, Vol. 281, No. 6, 1999.
- ⁸⁵⁻⁸⁹The Health Literacy Style Manual, Covering Kids and Families, October 2005, available at <http://coveringkidsandfamilies.org/resources/index.php?InfoCenterID=194>
- ⁹⁰⁻⁹¹Healthy People 2010, Health Communications, 11-6
- ⁹²Victor Strecher speaking at the Health Literacy: The foundation for Patient Safety, Empowerment, and Quality Health Care, national conference, June 26-27, 2006

Endnotes

- ⁹³Hablamos Juntos, www.hablamosjuntos.org
- ⁹⁴http://www.hablamosjuntos.org/signage/symbols/default.using_symbols.asp
- ⁹⁵⁻⁹⁸Marcus, Erin N., “The silent epidemic - The health effects of illiteracy,” *New England Journal of Medicine*, 355:4, July 27, 2006
- ⁹⁷DeWalt, Darren a., Berkman, Nancy D., Sheridan, Stacey, et al “Literacy and health outcomes: A systematic review of the literature,” *Journal of General Internal Medicine*, Volume 19, December 2004: 1228-1239
- ⁹⁸Osterberg, Lars, Blaschke, Terrence, “Adherence to medication,” *New England Journal of Medicine*, 353:5, August 4, 2005: 487-497
- ⁹⁹⁻¹⁰³National Quality Fourm, Implementing a National Voluntary Consensus Standard for Informed Consent, A User's Guide to Healthcare Professionals, 2005
- ¹⁰⁴Weiss, Barry D., Mays, Mary Z., et al, “Quick assessment of literacy in primary care: The newest vital sign,” *Annals of Family Medicine*, 3:514-522, 2005
- ¹⁰⁵Dr. Ruth Parker interview in Marcus article
- ¹⁰⁶Archie Willard speaking at the roundtable meeting
- ¹⁰⁷Marcus
- ¹⁰⁸⁻¹⁰⁹Ludmermer, Kenneth M. *Time to Heal: American Medical Education from the Turn of the Century to the Era of Managed Care*, Oxford University Press, 1999
- ¹¹⁰Roter, Debra L., Hall, Judith A., Aoki, Yutaka, “Physician gender effects in medical communication: A meta-analytic review,” *JAMA*, August 14, 2002 - Vol. 288, No. 6
- ¹¹¹USMLE, www.usmle.org
- ¹¹²⁻¹¹⁴Makoul, Gregory, “Communication skills education in medical school and beyond,” *JAMA* January 1, 2003, Vol. 289, No. 1
- ¹¹⁵IOM, *Health Professions Education*, p. 3
- ¹¹⁶⁻¹¹⁷Bedell, Susanna E., Graboys, Thomas B., et al, “Words that harm, words that heal,” *Arch Intern Med*, vol. 164, July 12, 2004
- ¹¹⁸⁻¹¹⁹Davis, TC, Dolan, NC, Ferreira, MR, “The role of inadequate health literacy skills in colorectal cancer screening,” *Cancer Investigation*, 2002;19(2): 193-200
- ¹²⁰Bedell, Graboys, et al
- ¹²¹Rothman, Russell L., DeWalt, Darren A., Malone, Robb, et al, “Influence of patient literacy on the effectiveness of a primary care-based diabetes disease management program,” *JAMA* 2004;292: 1711-1716
- ¹²²⁻¹²⁵IOM Health Literacy Roundtable presentation, September 14, 2006
- ¹²⁶⁻¹³⁰Osterberg
- ¹³¹⁻¹³²National Quality Fourm, Implementing a National Voluntary Consensus Standard for Informed Consent, A User's Guide to Healthcare Professionals, 2005

Endnotes

¹³³Schwartz, Lisa M., Woloshin, Steven, Welch, H. Gilbert, “Risk communication in Clinical Practice: Putting cancer into context,” *Journal of the National Cancer Institute*, Monographs No. 25, 1999

¹³⁴NAALS

¹³⁵⁻¹³⁶Edwards, A., Elwyn, G., “Understanding risk and lessons for clinical risk communication about treatment preferences,” *Quality in Health Care*, vol. 10, 2001

¹³⁷⁻¹³⁸Sepucha, Karen R., Fowler, Floyd J., Mulley, Albert G., “Policy support for patient-centered care: The need for measurable improvements in decision quality,” *Health Affairs*, October 7, 2004

¹³⁹Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the Twenty-first Century*, National Academies Press, 2001

¹⁴⁰Sepucha et al

¹⁴¹⁻¹⁴²Blumenthal, David, “Decisions, decisions: Why the quality of medical decisions matter,” *Health Affairs*, October 7, 2004

¹⁴³⁻¹⁴⁵IOM, *Health Literacy*

¹⁴⁶⁻¹⁴⁷<http://www.certs.hhs.gov/centers/houston.html>

¹⁴⁸IOM, *Health Literacy*

¹⁴⁹Joint Commission Resources, Patient Safety Essentials for Health Care, 4th edition

¹⁵⁰Landro, Laura, “Hospitals confront errors at the hand-off,” *The Wall Street Journal*, June 28, 2006

¹⁵¹⁻¹⁵⁵Joint Commission Resources, Patient Safety Handbook

¹⁵⁶Schnipper, JL, Kirwin, JL, Cotugno, MC, et al, “Role of pharmacist counseling in preventing adverse drug events after hospitalization,” *Archives of Internal Medicine*, 2006; 166: 565-571

¹⁵⁷⁻¹⁵⁸Federico, Frank, “Reconciling doses,” *AHRQ WebM&M*, November 2005

¹⁵⁹Bell, CM, Rahimi-Darabad, P., Orner, AI, “Discontinuity of chronic medications for patients discharged from the intensive care unit,” *Journal of General Internal Medicine*, 2006 Sep;21(9):937-41

¹⁶⁰⁻¹⁶¹Federico

¹⁶²⁻¹⁶⁵Joint Commission Resources Patient Safety Handbook

¹⁶⁶⁻¹⁶⁷Centers for Disease Control and Prevention, Chronic Disease Overview, www.cdc.gov

¹⁶⁸⁻¹⁷⁰IOM, *Health Literacy*, page 168

¹⁷¹Wagner, Edward H., Austin Brian T., Davis, Connie, et al, “Improving chronic illness care: Translating evidence into action,” *Health Affairs*, November/December 2001, Vol. 20, No. 6

¹⁷²⁻¹⁷³Bodenheimer, Thomas, Wagner, Edward H., Grumbach, Kevin, “Improving primary care for patients with chronic illness,” *JAMA*, October 9, 2002, Vol 288, No. 14

¹⁷⁴⁻¹⁷⁶Schillinger, Dean, “Improving chronic disease care for populations with limited health literacy,” Appendix B, *Health Literacy: A Prescription to End Confusion*, Institute of Medicine, National Academies Press, 2004

¹⁷⁷⁻¹⁷⁹Marcus

Endnotes

¹⁸⁰Dewalt et al

¹⁸¹National Center for the study of Adult Learning and Literacy, John Comings, Lisa Soricone, “Massachusetts: A Case Study of Improvement and Growth of Adult Education Services”

¹⁸²⁻¹⁸⁷Reach Out and Read, www.reachoutandread.org

¹⁸⁸⁻¹⁹¹Rudd, Rima, “When words get in the way: The importance of health literacy,” *Literacy Update*, vol. 13, No.3, January 2004

¹⁹²CMS, www.cms.gov

¹⁹³⁻¹⁹⁴Robert Mirsky, presentation at the “Mini -Conference on Health Literacy and Health Disparities,” Northwestern Hospital, July 21, 2005

¹⁹⁵Sepucha et al

¹⁹⁶⁻¹⁹⁸Hollmer, Mark, “Can sensitivity lower premiums?” *Boston Business Journal*, November 4, 2005

¹⁹⁹⁻²⁰⁰Hispanic Association of Corporate Responsibility

²⁰¹⁻²⁰⁴Speaking at Health Literacy: The foundation for Patient Safety, Empowerment, and Quality Health Care, national conference, June 26-27, 2006

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