

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 Organization 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 litera-

cy 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.

Executive Summary

- 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 system 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.

Executive Summary

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.

Executive Summary

- 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.

Executive Summary

- 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.