Toward Health Equity and Patient-Centeredness: Integrating Health Literacy, Disparities Reduction, and Quality Improvement: Workshop Summary

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TOWARD HEALTH EQUITY AND PATIENT-CENTEREDNESS

Integrating Health Literacy, Disparities Reduction, and Quality Improvement

WORKSHOP SUMMARY

Samantha Chao, Karen Anderson, and Lyla Hernandez,
Rapporteurs

Forum on the Science of Health Care Quality
Improvement and Implementation

Roundtable on Health Disparities
Roundtable on Health Literacy

Board on Health Care Services
Board on Population Health and Public Health Practice

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> *Willing is not enough; we must do."*
> —Goethe

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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the final draft of the report before its release. The review of this report was overseen by **CARMEN R. GREEN, M.D.,** Health Disparities Research Program, Michigan Institute for Clinical and Health Research. Appointed by the Institute of Medicine, she was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authors and the institution.

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1

Introduction

The United States has experienced vast demographic changes, especially in the last generation; new populations have emerged as immigrants disperse across the country and form new communities in different states. Such demographic shifts affect health care in a variety of dramatic ways, particularly in the way health care is delivered. With more diverse cultures and languages, health care providers now must tailor the health care they provide to individuals to ensure that care is equitable and patient-centered. Delivering equitable health care and focusing on the individual has incidentally elevated health care disparities and health literacy as major health care topics. Providers are beginning to use tools to improve care delivery in these areas, such as providing patients with appropriate medication instructions in their primary language and offering translation services—tools that could lead to vast improvements in the care patients receive. Quality improvement, with a focus on reducing health care disparities and enhancing health literacy, is vital to assuring better health for the nation now and for future populations.

Ignatius Bau, J.D.
The California Endowment

Health care issues are important to the national dialogue. Unfortunately, the emphasis of this dialogue has focused on issues of insurance and coverage in the reformation of health care with little discussion of quality, disparities, and health literacy. Race, gender, class, and age can define us as well as divide us. Yet, to improve quality, reduce health disparities, and enhance health literacy, the principles of equity and patient-centeredness in health care must drive the discussion of health care reform.

The reports *To Err Is Human: Building a Safer Health System* (IOM, 2000) and *Crossing the Quality Chasm: A New Health System for the 21st Century* (IOM, 2001) focused attention on the need to improve the quality of health care in the United States. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (IOM, 2003) explored the ways in which race and ethnicity are significant predictors of the quality of health care received. This report also highlighted the importance of not exacerbating the health disparities that do exist in the pursuit of quality. Finally, *Health Literacy: A Prescription to End Confusion* (IOM, 2004) highlighted the importance of health literacy to health outcomes and the provision of high-quality health care and illustrated the need for communication in the health care context that is clear and effective. Together, these reports illustrate that reducing health disparities and improving health literacy are important components of increased quality in health and health care for the American public.

While the reduction of health care disparities focuses on populations experiencing and suffering from inequities, its impact is much broader. Interventions to improve access to care and quality of care for populations experiencing the greatest disparities can also positively affect others. For example, ramps for the disabled can also be used by those pushing strollers, and large print and more "plain English" signs and labels are beneficial to those with vision impairments and low health literacy, thereby benefiting us all. Ultimately, reduction of health care disparities requires that prevention of disease and morbidity be addressed, requiring broader and longer-term interventions at the population and community levels.

Similarly, many interventions that address the needs of specific populations can benefit other populations, as providers can learn to adapt these skills in the care of all patients, allowing for clearer, more effective communication and increased patient understanding and engagement in their own treatment and care. Efforts to make the health care system more equitable can therefore benefit the whole population, not just targeted populations. Achieving equity requires changes at the systems level not for the purpose of segregating the population but rather for the purpose of respecting patients' cultural, spiritual, and religious beliefs and individual needs.

To examine the role of quality improvement in improving health literacy and reducing racial and ethnic disparities, as well as geographic disparities, the Institute of Medicine Forum on the Science of Health Care Quality Improvement and Implementation, the Roundtable on Health Disparities, and the Roundtable on Health Literacy agreed to collaborate on a workshop. A planning committee[1] consisting of members of the three convening bodies as well as other experts in the field organized the workshop, Toward Health Equity and Patient-Centeredness: Integrating Health Literacy, Disparities Reduction, and Quality Improvement, which was held on May 12, 2008.

THE WORKSHOP AGENDA

The workshop began with the presentation of a vision for integrating disparities reduction, health literacy, and quality improvement to achieve better outcomes, followed by a panel of speakers who addressed building a foundation for integration of these three areas. A second panel addressed using quality improvement as a tool to improve health literacy and reduce disparities at the practitioner level. During the afternoon, breakout groups met and reported back on their discussions of three questions:

- What specific activities could be undertaken to effectively integrate quality improvement, disparities reduction, and improved health literacy?
- How can such integration be more patient-centered?
- What systems integration and systems changes might be necessary to achieve greater patient-centeredness and equity?

A third panel discussed policy issues related to integration, including standards and priorities that could foster improvement in patient-centered care and equity; types of measures that could be developed to understand the contributions of health literacy and disparities reduction to improved quality; how efforts at integration could be evaluated; and issues of financing, education, and training. The workshop concluded with remarks from the chairs of the three convening bodies.

The following is a summary of the presentations and discussion of the workshop and, as such, is limited to the views presented and

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[1] The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop.

discussed during the workshop. The broader scope of issues pertaining to this subject area is recognized but could not be addressed in this summary. Appendix A is the workshop agenda and Appendix B lists workshop participants.

2

Opportunity at the Intersection of Quality Improvement, Disparities Reduction, and Health Literacy

George Isham, M.D., M.S.
HealthPartners

It is imperative for health care systems to understand that reducing health disparities and addressing health literacy are important strategies for improving health care system quality. Before exploring the integration of these three concepts, it is worthwhile to explore each component separately. More specifically, Isham spoke about the following issues:

- The state of quality improvement research, variations in quality of care, and the rate of improvement in the United States;
- Health disparities in the United States, progress in addressing health disparities, and health care system strategies to address disparities;
- Health literacy and "the perfect storm" of declining literacy levels, an increasingly diverse population, and a large level of expected job growth in knowledge-intensive work environments; and
- Ideas for improving disparities in health care and health literacy, including the use of a medical home model, changes in the structure of the care delivery system, and using evidence-based medical practices.

QUALITY

The United States has the most expensive health care system in the world. In spite of that, health care is of inconsistent quality and leads to poorer health outcomes relative to other, similar nations; for example, the United States has much higher infant mortality rates.[1]

There are many types of quality problems. There is overuse, underuse, and misuse of care. For example, for overuse of health care, 30 percent of children receive excessive antibiotics for ear infections, 20 percent to 50 percent of many surgical interventions are unnecessary, and 50 percent of X-rays in back pain patients are unnecessary. Underuse can be seen in data that show that 50 percent of the elderly fail to receive the pneumococcal vaccine. Misuse is illustrated by the 7 percent of hospital patients who experience a serious medication error and the 44,000 to 98,000 Americans who die in hospitals each year due to injuries from care (Berwick, 2004). Other types of waste include administrative waste, process waste, and geographic variation in how health care is delivered. Administrative waste is largely a function of the fragmented health care system and a fragmented public health system. Waste is exacerbated when a fragmented health care system interacts with the broader determinants of health. Administrative waste is one area that demonstrates why one should consider the levels of organization of care along with the processes and outcomes of care when considering areas for quality improvement.

As outlined in the 2007 *National Healthcare Quality Report (NHQR)* (AHRQ, 2008a), there are also variations in the quality of care delivered across the country. The report also indicates that although health care quality is improving, the rate is slow, and safety is improving at an even slower rate. Progress is not as rapid as it should be.

The 2001 Institute of Medicine (IOM) report, *Crossing the Quality Chasm* (IOM, 2001) outlined six aims to improve the quality of health care. The six aims are that health care should be *safe, effective, patient-centered, timely, efficient*, and *equitable*. These six aims address not only process improvement but improvement that needs to occur at multiple levels within the health care system (see Figure 2-1). It is not enough to change the payment and regulatory environment; health care organizations and teams providing care must be sup-

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[1] Of the infant mortality rates reported for 32 developed countries, the United States had higher infant mortality than 30 other countries, ranking above only the country of Latvia (Nordquist, 2006).

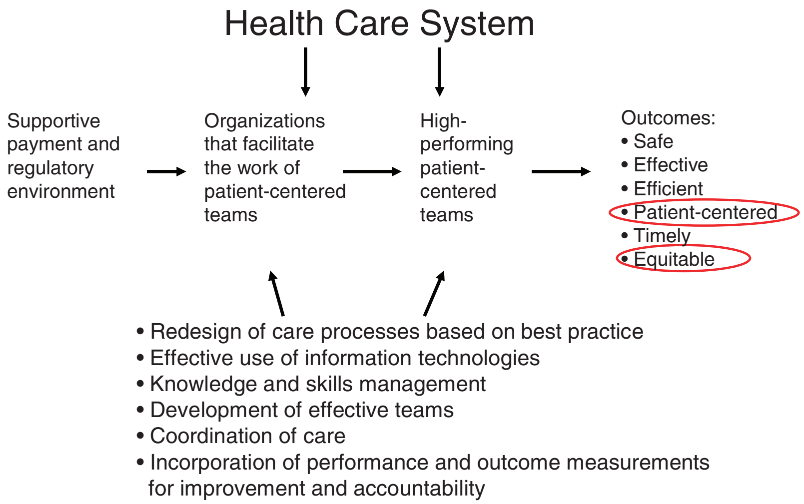

FIGURE 2-1 The health care system.
SOURCE: IOM, 2001.

ported as well. These changes in turn will lead to better patient outcomes. The aims have led to much debate and discussion about changes in the structure and organization of care. However, the aims of patient-centeredness and equity are not as well represented by quality measures or improvement efforts as the other aims. These two aims deserve better measurement, better data, and stronger improvement efforts.

It is not enough to focus on quality; disparities must be addressed as well. This is an important consideration, as health care outcomes show significant disparity by race, ethnicity, and education level.

DISPARITIES

Disparities are defined as "racial or ethnic differences in the quality of health care that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention" (IOM, 2003). The findings from the IOM report *Unequal Treatment* are summarized as follows:

1. Disparities exist and are unacceptable.
2. Disparities occur in a broader social context.

3. There are multiple sources of disparate treatment.
4. Bias, stereotyping, prejudice, and clinical uncertainty may all play a role in health disparities.
5. Minority patients may be more likely to refuse treatment than white patients. (However, minority refusal rates do not fully explain health disparities.)

The report's recommendations on reducing health disparities include raising general awareness about disparities; legal, regulatory, and policy interventions; health care systems interventions; public education campaigns and efforts to empower racial and ethnic minority patients; increased amounts of cross-cultural education and training for health care professionals; better data collection and monitoring; and greater amounts of research on disparities.

Unequal Treatment states that improving the consistency and quality of care via the establishment of evidence-based guidelines is an important task. Evidence-based guidelines emphasize standardization, while patient-centeredness suggests the need for tailoring care to individual patients. Other recommendations include the creation and maintenance of payment systems to ensure an adequate supply of services to racial and ethnic minority patients, enhancing communication and trust between providers and patients via the provision of incentives for practices that reduce barriers to high-quality health care and encourage the adoption of evidence-based practices, provision of greater support of interpreter services and community health workers, and the implementation of multidisciplinary teams for the provision of care.

Despite these IOM recommendations, a more recent report, the *2007 National Healthcare Disparities Report (NHDR)* indicates little progress in reducing racial and ethnic health disparities (AHRQ, 2008b). In other words, there is still much progress to be made.

Perhaps the best way to begin thinking about a set of priorities for reducing health disparities is to consider the three largest disparities in health care quality for racial and ethnic minorities as outlined in the 2007 *NHDR* (see Table 2-1). Taking this approach may allow for the development of some ideas in the health care community about how to begin to address these most important disparity issues in health care systems, which are beginning to collect data. One of the themes from this table is the importance of effective communication, as noted in the bolded sections in the table.

In current quality measures, such as the Healthcare Effectiveness Data and Information Set (HEDIS) of the National Committee on Quality Assurance, current measures do not adequately measure disparities. One must be careful about applying risk-adjustment methods to current performance measures. Care must be taken to ensure that in the process of risk adjustment, the differences of interest are not simply adjusted out.

Finally, there is variation within health care organizations that compromises the delivery of quality care. This variation in health care delivery to diverse populations of patients is a legitimate target for quality improvement efforts. The generation and collection of data by racial and ethnic group category is a first step that can assist in developing quality improvement efforts. Good data are needed to build a foundation for improvement.

Health care systems' strategies to reduce disparities include setting disparities reduction goals that are then incorporated into contracts and performance incentives. For example, the HealthPartners system in Minnesota has goals and objectives related to both disparities reduction and the improvement of health literacy. Measures of disparities and the skills to collect and assess them are also important, as is the development of additional interventions known to reduce disparities.

Successful approaches should include making efforts to reach out to the local community in order to understand the context in which people live. Lastly, delivering culturally and linguistically appropriate care at all levels of the health care delivery system is important.

HEALTH LITERACY

The final strand for integration is health literacy, "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan and Parker, 2000). Research shows that a substantial percentage of the American population does not have the capacity to adequately understand and use health information (IOM, 2008). Health literacy is a shared function of social and individual factors such as education, culture, and language. Additionally, health care providers need to have strong communication and assessment skills as do the media, the marketplace, and government agencies—to provide health information in a manner appropriate to the intended audience. The complexity of the health care system and the way patients experience it contribute to the difficulty of being health literate. Addressing health literacy is no less daunting than the task of addressing disparities.

TABLE 2-1 Largest Disparities in Health Care Quality for Selected Groups: 2005 versus 2007 *NHDR*[a]

Group	2005 NHDR		2007 NHDR	
	Measure	Relative rate	Measure	Relative rate
Black	New AIDS cases per 100,000 population age 13 and over	10.4	New AIDS cases per 100,000 population age 13 and over	10.0
	Hospital admissions for pediatric asthma per 100,000 population ages 2–17	4.0	Hospital admissions for pediatric asthma per 100,000 population ages 2–17	3.8
	Percent of patients who left the emergency department without being seen	1.9	Hospital admissions for lower extremity amputations in patients with diabetes per 100,000 population	3.8
Asian	Persons age 18 or older with serious mental illness who did not receive mental health treatment or counseling in the past year	1.6	Composite: Adults who reported poor communication with health providers	1.6
	Adults who can sometimes or never get care for illness or injury as soon as wanted	1.6	Long-stay nursing home residents who were physically restrained	1.5
	Adults age 65 and over who did not ever receive pneumococcal vaccination	1.5	Adults age 65 and over who did not ever receive pneumococcal vaccination	1.5
AI/AN[b]	Women not receiving prenatal care in the first trimester	2.1	Women not receiving prenatal care in the first trimester	2.1

	Composite: Adults who reported poor communication with health providers	1.8	Composite: Adults who reported poor communication with health providers	1.8
	Children ages 2–17 with no advice about physical activity	1.3	Women age 40 and over who reported they did not have a mammogram within the past 2 years	1.8
Hispanic	New AIDS cases per 100,000 population age 13 and over	3.7	New AIDS cases per 100,000 population age 13 and over	3.5
	Adults who can sometimes or never get care for illness or injury as soon as wanted	2.0	Hospital admissions for lower-extremity amputations in patients with diabetes per 100,000 population	2.9
	Composite: Children whose parents reported poor communication with their health providers	**1.8**	Women not receiving prenatal care in the first trimester	2.0
Poor	**Composite: Children whose parents reported poor communication with their health providers**	**3.3**	**Composite: Children whose parents reported poor communication with their health providers**	3.0
	Adults who can sometimes or never get care for illness or injury as soon as wanted	2.3	Adults who can sometimes or never get care for illness or injury as soon as wanted	2.4
	Children ages 2–17 who did not have a dental visit	2.0	Women age 40 and over who reported they did not have a mammogram within the past 2 years	2.1

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[a] *NHDR* = *National Healthcare Disparities Report*.

[b] AI/AN = American Indian/Alaska Native.

SOURCE: AHRQ, 2008b.

How is health literacy considered in the context of quality improvement? Although data that assess the health literacy skills of a particular individual can be collected, there is no similar assessment for the health care delivery organizations. From the perspective of health literacy, the interface of the health care system with an individual is very complex, and this complexity can lead to fragmented care, different communication strategies across multiple providers, and complicated efforts that require a high level of coordination to achieve the effective management of chronic disease. The problem is twofold. First, there is the problem of the differing capability of individuals to understand health information. Second, there is the problem of the technically complex subject, language, and process of care. We lack the measurement tools to assess patient literacy in patient populations served by operating health care systems. Quality measures for improving health literacy are lacking.

In the United States today, 90 million people have inadequate levels of health literacy (IOM, 2008). A low level of health literacy is associated with a number of negative health outcomes, including less use of preventive services, greater use of hospitals and hospital emergency rooms, poor general health and mental health, and an increased risk of death.

The IOM report *Health Literacy: A Prescription to End Confusion* (IOM, 2004) outlined potential interventions to address raising levels of health literacy in three areas: the health care system, the education system, and in culture and society. Low health literacy is not just a problem for the health care system; it is a broader societal issue. Figure 2-2 provides a health literacy framework for potential points.

THE PERFECT STORM

The Educational Testing Service predicts a 5 percent decline in health literacy for 16- to 65-year-olds, suggesting that the problem of health literacy will worsen. Ruth Parker and colleagues (2008) called a future that holds declining health literacy levels, shifting demographic patterns, and a changing job market "the perfect storm."[2]

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[2] The high school graduation rate in the United States is stagnant and has been since the mid-1990s. The American population is increasingly diverse, owing to a large growth in the number of new immigrants. Many of these immigrants speak little or no English, and all have diverse backgrounds and educational experiences. Additionally, half of the expected job growth in the coming decade is predicted to be in "knowledge-intensive" work sections where high literacy proficiency is required. Coupled with an aging population of well-educated workers who are ready to retire, this signals a coming shortage of skilled workers (Parker et al., 2008).

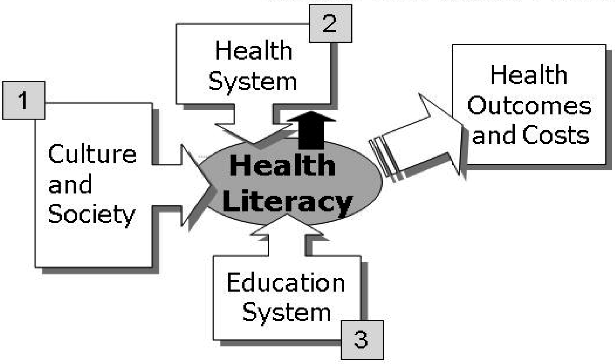

FIGURE 2-2 Health literacy framework.
SOURCE: IOM, 2003.

The consequences of this perfect storm include higher numbers of unemployed and uninsured workers and even greater problems of health care quality, cost, and disparities.

So how does the United States prepare for the storm? Parker et al. (2008) suggest that the following needs to occur: Use data to identify the most vulnerable populations; tailor our interventions to fit high-risk populations; simplify materials so they are tailored to the individuals being served; and, in the longer term, help build health literacy through education systems so patients can better act on their own behalf in the health care setting. Finally, it is critical that an organizational infrastructure be created to support the growing need to meet patients where they are today.

Health Literacy and Health Disparities

Racial and ethnic minorities are far more likely to be below basic or at basic levels in their health literacy. With the exception of Asian/Pacific Islanders, racial and ethnic minorities are also less likely to be proficient in understanding health information. It seems clear that a lack of health literacy skills contributes to health disparities. However, it is important to note that health literacy is a problem that affects all racial and ethnic groups (see Figure 2-3).

In addressing health disparities and health literacy, it is critical to deliver culturally competent and sensitive care and to reach out by engaging patients at their differing levels of capability.

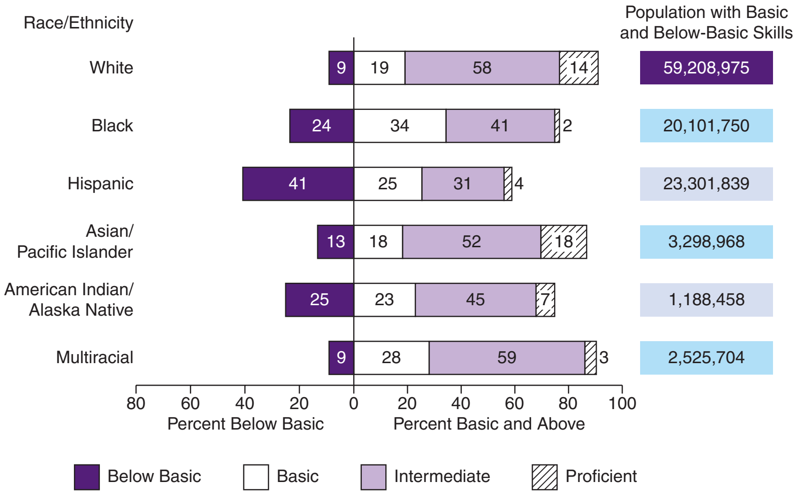

FIGURE 2-3 Health literacy by race and ethnicity. *Below basic* is the lowest level of performance and includes tasks such as signing a form or adding the amounts on a bank deposit slip. *Basic* means that a person can perform simple, everyday literacy tasks such as understanding a pamphlet describing how a person gets chosen for jury duty. *Intermediate* means that a person can do moderately challenging tasks such as identifying a specific location on a map. *Proficient* means that a person can perform complex activities such as interpreting a table about blood pressure and physical activity (NCES, 2005).
SOURCE: AHRQ, 2008b.

Poor patient–provider communication is not only a factor contributing to poor patient health literacy; it also is related to racial, ethnic, and income disparities (AHRQ, 2008b). Racial and ethnic minority groups were more likely to report poor communication with their health care provider. Income level, too, is a factor; lower-income groups are more likely to report poor communication.

Although patient–provider communication is important, it is also worth noting that the individual spends only a small proportion of his total life with his physician. Rather, people are left to make health decisions on a daily basis on their own behalf. This compounds the difficulty of increasing health literacy, and, in turn, remains a significant barrier to improving health care quality.

Improving Disparities in Health Care and Health Literacy in Care Systems

The processes of care must be reenvisioned to facilitate equitable patient-centered care. HealthPartners developed a "care model process" that attempts to standardize care at the point of service to the patient with the objective of providing the same evidence-based high standard of care to all patients. The early experience with standardized care processes[3] suggests that quality of care can be improved and disparities in care narrowed. What has not received as much attention, however, is postvisit and between-visit care.

The medical home model as articulated by the primary care specialty societies may present tremendous opportunities for better coordinating the care of patients. It is possible that this model could also serve as a vehicle to reach out to patients in culturally sensitive and appropriate ways and work with them to improve their health literacy skills beyond basic or below basic levels.

However, in addition to addressing the processes of care, changes in the structure of the care delivery system must also be considered. Tolen (2008) describes the nature of physician organizations as they relate to quality and efficiency of care using the structure, process, and outcome framework developed by Donabedian (1966). As was mentioned earlier, it is important to think about the complexity of the interface of the health care system in relationship to the health literacy of the individual patient. However, there has been very little discussion in health care reform about how to provide the kinds of infrastructure and support to enable health care organizations to improve quality and deal with the challenges of complex interactions between quality improvement, health disparities, and health literacy.

Providing equitable, patient-centered, high-quality care is not only an issue of an individual clinician dealing with a patient. It is also how the health care organization is configured to deal with diverse populations and literacy issues in the context of the neighborhood and broader community where the clinic resides.

Evidence-based medical practices help to standardize care to ensure that the same high quality is available to all. This can result in reduced disparities in care. There is also the need to customize that evidence-based standard to the culture and preferences of the individuals served and tailor the approach to maximize the outcome

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[3] Standardized care processes are defined as care that meets all of the desirable quality attributes as identified in *Crossing the Quality Chasm* (IOM, 2001).

for patients with all levels of health literacy skills. Changing health care systems requires more than just looking at the *processes* of care; the *structures* of care must also be considered. These structures need to have the ability to deliver better patient care that is better tailored to the individual needs of patients, both on the individual level and the population level.

NEXT STEPS

To improve quality of health care by addressing health literacy and health disparities, the following steps need to be implemented. First, leadership and vision with explicit long- and short-term goals are critical. These goals should relate not only to health care, but also to health care disparities and health literacy. Second, care standards that reduce the existing variation in recommending evidence-based care must be implemented while recognizing that at times, care must also be customized. This involves incorporating the values and preferences of individual patients and considering their individual skills and abilities.

A robust research agenda focusing on health literacy and health disparities is critical to ensure that patient-centered care becomes incorporated as a critical underpinning in all quality improvement efforts. Shared decision-making skills in the health care delivery system are critical, as is the creation and implementation of effective interventions by trained teams with appropriate skills. Quality improvement through disparities reduction and improved health literacy also requires redesigned and optimized care structures and processes, coordinated and integrated care, and effective use of information technologies as a part of process redesign.

It is necessary to create and use performance measures by racial or ethnic group, health literacy capability, and complexity of care interface, as well as to include incentives for improvement of performance measures. Finally, the integration of quality, disparities reduction, and health literacy requires community collaborations with both the public and private sectors.

3

Building the Foundation for Integrating Health Literacy, Disparities Reduction, and Quality Improvement in Health and Health Care

A panel of experts discussed the urgency of creating, maintaining, and strengthening the intersection between health literacy, health disparities, and quality improvement.

HEALTH LITERACY: A MATTER OF HEALTH CARE QUALITY AND EQUITY

Michael Wolf, Ph.D., M.P.H.
Northwestern University,
Feinberg School of Medicine

The following discussion on integrating quality, disparities reduction, and improvement in health literacy is primarily from the perspective of health literacy. As Isham mentioned earlier, there is a looming epidemic of low health literacy. Developing strategies to address low health literacy and its impact on health is problematic, partly because it is very difficult to untangle the contribution of literacy issues to health outcomes from many disparities issues. For example, the relationship between levels of education and health has long been known; research has established a link between low levels of education and poor health outcomes, including a greater mortality risk (NCHS, 1998; Lleras-Muney, 2002; IOM, 2006). This research, however, has not identified clear causal pathways for the relationship.

Over the past two decades, research has examined the issue of low literacy and its impact on health. Of the more than 1,600 articles in the health literacy research literature, about half address the issue of written health information that is too complex for understanding by the average adult American who reads at an eighth-grade level. The other 800 articles focus on the link between poor literacy, poor reading skills, or poor health literacy and various health outcomes such as increased mortality.

In exploring the link between literacy and mortality, Baker and colleagues (2007) found that a clear correlation exists between inadequate health literacy and increased mortality rates (see Figure 3-1). In fact, the study showed that there is a 50 to 80 percent increased mortality risk for people with inadequate health literacy. Importantly, the study also found that poor health literacy is a stronger indicator of mortality risk than overall years of schooling.

Data from the National Health Literacy Survey of 1992 and the 2005 National Assessment of Adult Literacy show that African Americans and Hispanics are overrepresented in the lowest levels of literacy proficiency (Kutner et al., 2006). This also parallels the

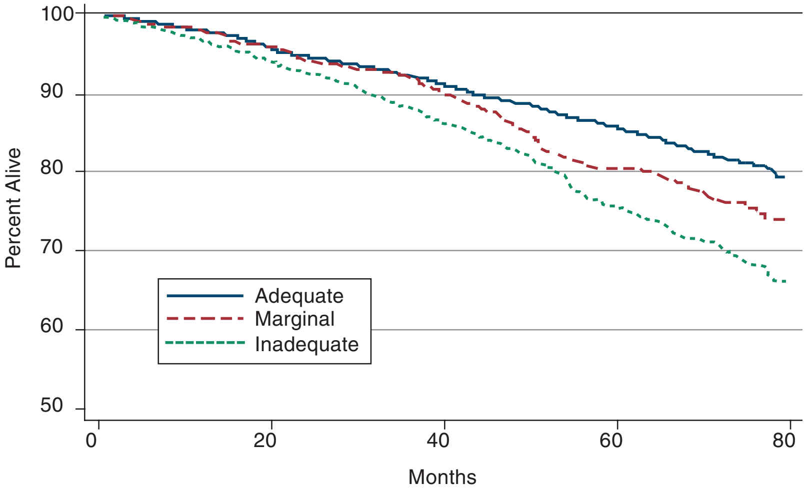


FIGURE 3-1 Those with inadequate health literacy had higher mortality rates than those with adequate or marginal health literacy. Literacy and mortality risk are of the study population ($n = 3260$ Medicare managed care enrollees). Literacy is assessed by a shortened version of the Test of Functional Health Literacy in Adults. Results are adjusted for age differences.
SOURCE: Baker et al., 2007. Copyright © (2007) American Medical Association. All rights reserved.

high school dropout rate in the United States; Hispanics have the highest drop out rate (22 percent), followed by African Americans (10 percent) and whites (6 percent) (Laird et al., 2007). The strong association between literacy and education as measured by staying in school is clear.

More recent research has examined whether literacy may be a mediating factor in health disparities, thus helping to explain poorer health outcomes for racial and ethnic minorities. When health literacy is taken into account, there is a 25 to 30 percent reduction in the relationship between race/ethnicity and health outcomes, Wolf said.

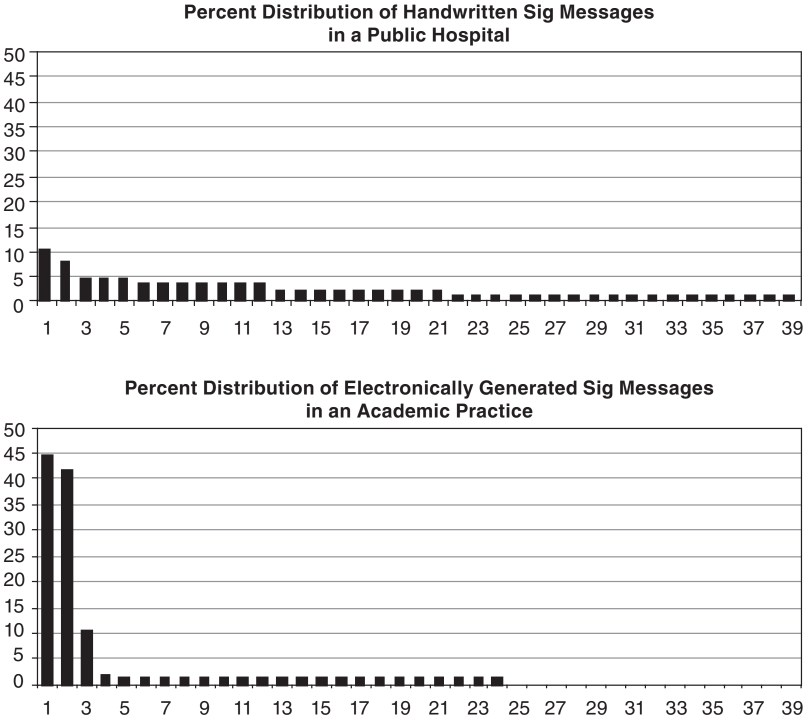
Health Literacy and Quality

How information is delivered to patients is an indicator of quality. This may be a particularly important indicator in the ambulatory setting, where the patient, not the provider, plays the key role in implementing care instructions received during what may have been brief encounters with the physician. Bailey and colleagues (2009) conducted a study that examined how medication instructions were written in two health care systems, one a county hospital and the other an academic medical center with an electronic health record system.

The study found that in the county hospital, the medication instruction “take one tablet a day” was written in 39 different ways (see Figure 3-2). In the academic medical center, the study found 54 different ways to enter the instruction “take one tablet a day.” It should be noted, however, that most of the instructions were entered in one of three preprogrammed ways provided by the electronic system, indicating that in most cases the physician is using the given dosage instructions. Rarely is the physician making modifications to the given dosage instructions.

As far as medication instructions, then, there is a simple fix—standardize the system. Patients require clear, consistent, standardized information so that they have clear expectations about what they need to do.

Results from a study that surveyed how 96 pharmacies recorded instructions for the same four prescriptions illustrate why patients make unintentional medication errors. For some, important auxiliary warnings are not included, as was the case with the medication Fosomax. If this pill stays in the esophagus, it causes irritation; therefore, instructions to remain upright and take fluids are crucial. Thirty-five of the instructions did not provide this warning. No men-



Percent Distribution of Handwritten Sig Messages in a Public Hospital

Percent Distribution of Electronically Generated Sig Messages in an Academic Practice

FIGURE 3-2 Variation in prescription instruction. Greater variation occurs in the nonstandardized system (top graph) than in the standardized system (bottom graph).
SOURCE: Bailey et al., 2009.

tion was placed on the bottle for this very significant precautionary comment.

The study also found that Latin abbreviations and medical shorthand appear on the medication; for example, one medication stated that it was "for UTI," and this appeared on the bottle. Some patients might not recognize that this is an abbreviation for "urinary tract infection." Furthermore, a medication label might instruct "take one tablet at bedtime" or "take one tablet daily" with no suggested administration time. Patients may become confused about when to take the medication or may not take it consistently over time.

As these studies demonstrate, communication with patients about how to take medications is highly variable. Knowledge gained about how to enhance and clarify medication information to support patient comprehension has not been incorporated into information for patients. Consumer medication information (CMI) sheets are intended for distribution to consumers when a prescription is filled. This information is developed by organizations or individuals other than a drug's manufacturer. However, the CMIs are usually long and hard to understand; the average American adult reads at the eighth-grade level yet the majority of CMIs are written at a high school level or above. One study (Wolf et al., 2006) found that fewer than one-third of patients bothered to review the materials accompanying their prescriptions; rather, they were discarded with the bag. As a quality indicator, this is troubling.

It is also the case that physicians and pharmacists do not routinely engage in verbal counseling with patients about how to take newly prescribed medications (Metlay et al., 2005; Tarn et al., 2006). Physicians are routinely reported to be the most trusted source of health information and, for patients with low health literacy, the prescribing physician may be the only source of health information. Yet rarely is an effort made to confirm understanding with the patient in an active, rather than passive, way—for example, by asking the patient to "tell me what you heard" or do a "teach-back." Consequently, patients across all literacy levels may have a less than optimal understanding of their diseases and treatments, which is likely to affect their ability to manage their health. For example, adverse drug events are associated with patient misunderstanding of instructions (Davis et al., 2006).

There is discordance between individual levels of health literacy and the complexity of communication from the average health care system in the United States. The interface between the user of health care and the health care system must be simplified. There must be clear, concise, and consistent information delivered in a standardized manner. Patient comprehension must be supported so that patients will understand and take needed actions. Health literacy is an essential part of patient-centered care and of quality care.

The future is not bright for increasing the health literacy of the American population. Parker and colleagues (2008) predict that by 2030 there will be a greater percentage of patients scoring in the lowest levels of proficiency in literacy and stagnating high school graduation rates. Although there has always been the problem of a large proportion of adults with insufficient levels of literacy to effectively engage the health care system, it appears that the proportion is going to grow substantially larger. The growing immigrant population will struggle with issues of health literacy. In the changing economy there will be growth in knowledge-intensive jobs with less focus on the unskilled labor force. How will all of this affect the health care system?

Call to Action

The thrust for action in quality improvement should target four areas: patient skills, health materials, clinician skills, and health care system design. For patient skills, it is necessary to determine the knowledge patients need to effectively engage with the health care system. Best practices for writing health materials, how to display information over the Internet, and how to successfully deliver health materials in multimedia formats must be identified to improve the way in which information is communicated with patients.

Health professionals need training in how to communicate the complex body of medical knowledge in ways that patients can understand. Finally, the system must ensure that patient education is a sustainable component of health care system design, which may in turn require new thinking about approaches to the delivery of health care.

In the health literacy arena, new research is underway to test whether an evidence-based, enhanced label design for prescription drug containers improves older patients understanding of instructions for use. Increased understanding of the instructions found on prescription drug labels may well lead to increased patient comprehension, improved medical adherence, and improved health outcomes.

The enhanced label will include a uniform medication schedule that helps to present the information visually for the patient. The uniform medication schedule, developed originally by Alastair Wood (2007), and a standardized prescription form that would have a schedule for taking medication that includes breakfast, lunch, dinner, and bedtime, are seen as tools to link what are now two discordant worlds, the world of pharmacy and the world of medicine. Creating patient-friendly prescriptions also requires eliminating Latin abbreviations.

Electronic health records can also assist in the promotion of health care quality by serving as a tool for standardizing communication approaches with patients.

The crucial question is, how are we supporting patients to engage in actions that promote their health? Attention needs to be directed to how education researchers are designing literacy curricula and to understanding how human factors researchers consider complex systems. Strategies to incorporate culturally competent care with patient populations must be developed. Finally, Wolf concluded, sustainable solutions should be embedded across the continuum of care.

INTEGRATING HEALTH LITERACY, DISPARITIES REDUCTION, AND QUALITY IMPROVEMENT

Cindy Brach, M.P.P.
Agency for Healthcare Research and Quality

There are a number of ongoing conversations that focus on whether cultural competence is a part of health literacy or vice versa. Other conversations focus on how to integrate cultural competence into the mainstream quality movement. This workshop is designed to bring these conversations together. These conversations are very important if we are to move the field forward without wasting vital energy on separate efforts.

Major Connections Between Health Literacy and Disparities

There are several strong connections and commonalities between health literacy and disparities. First, efforts to advance health literacy and to reduce disparities both focus on improving communication. Clinicians have a Western medical perspective that may not be shared by the patient either because of limited health literacy or cultural differences. Clinicians need to ask themselves such questions as, "Does my patient share my understanding of how the body works?" It is critical to communicate information so that the patient understands and can act upon it, and that entails meeting the patient where he is, rather than making assumptions.

A second connection common to health literacy, cultural competence, and disparities reduction involves overcoming language barriers. A common solution to language barriers is to translate relevant materials. However, if the health literacy level in the native language is not taken into account, the translation may not be effective at imparting needed information. For example, a study that examined Latino patients' understanding of prescription medication instructions after the instructions were translated into Spanish found that only 22 percent could correctly demonstrate how to use the medication (Leyva et al., 2005).

Even if health literacy has been addressed in the English version of a document, care must be taken that plain language is also used in the translation. For example, the Office of Human Research Protections (OHRP) created an English-language brochure outlining the elements of informed consent. The brochure, which did a good job of explaining complex concepts using simple language, was then translated into Spanish. Unfortunately, the language used in the Spanish translation was much more complex and the level of abstraction was higher than in the original brochure. This translation was, therefore, much more difficult to understand, demonstrating the importance of considering health literacy and cultural competence together when addressing language barriers for patients.

Finally, health literacy and disparities are connected by health beliefs. For example, one study showed that a group of African American women in New Orleans shared a belief that high blood pressure is actually two separate diseases, rather than one. They believed that "high blood" and "high pertension" are different diseases and that hypertension medication only works with "high blood" disease. So if one of these women thought that she had the "high pertension" disease, she would not believe that taking medication would help (Heurtin-Roberts and Reisin, 1992). From a health literacy perspective, these women clearly do not understand how their bodies work or that medication could help. From a disparities reduction perspective, these women held cultural health beliefs at odds with Western medical concepts. Regardless of the perspective, clinicians need to explore the health beliefs of their patients and come to a common understanding.

Strategies for Connecting Health Literacy and Health Disparities

One strategy for addressing health literacy and health disparities in the context of quality improvement is to develop specific quality improvement projects that address both issues. For example, an organization might choose to embark on a quality improvement project aimed at improving health education materials. In that case, the organization might look at the mismatch between health education materials and the level of complexity or readability of the materials, their cultural relevance, and whether the available language translations suitable for the patient population served are available. Furthermore, health care systems could foster more stigma-free environments. This would entail making sure the environment, including signage, was welcoming regardless of health literacy, English proficiency, or national origin.

Another quality improvement project could be to improve clear communication and shared decision making. However, some cultures believe in being deferential to those in positions of authority.

Some also believe that it is insulting to ask the health care provider questions. All quality improvement efforts should therefore be cognizant of cultural, health literacy, and disparities issues.

Another strategy for addressing health literacy and health disparities is to integrate health literacy and disparity reduction into all quality improvement activities. This addresses the concern expressed by some that quality improvement efforts could actually increase disparities. If incorrect assumptions are made about individuals and communities being served (as in the example above), it is possible that only certain segments of a population will benefit from a given quality improvement strategy. Those who are most vulnerable may be left further behind. To address this possibility, one could test the quality improvement strategy in a demonstration project with a set of diverse patients before implementing it widely. Such a test would make it possible to gather information about how the strategy works with different subgroups being served and allow for modifications to be made for the best care possible.

Another approach to integrating health literacy and disparities is to examine the complexity of the health messages that patients receive and the demands made of patients in the health care setting, rather than on individual patient skills and abilities. A simple but important step is to facilitate a patient's ability to locate the office or the treatment room in a health care facility. Facilities have addressed this by changing their signage, using maps, icons, and multiple languages to help patients find their way.

Typically, once the patient arrives at the correct destination, he or she must complete a large number of forms. Many adult learners say that this is the scariest thing about going to see a doctor, perhaps even keeping some individuals from visiting the physician's office. Patients are expected to provide their own medical histories as well as describe their current symptoms. This requires an understanding of what is important information to share and what is not. Further, because quality improvement efforts suggest that patients be a part of decision making, the expectation is that the patient will ask questions of the provider. If a referral is made to a specialist or for laboratory tests, the patient is expected to follow up on his own. The patient is also expected to adhere to the prescribed medication regimen and to engage in self-management of his or her health conditions. As Wolf described earlier, medication instructions are often far from clear, and complexity increases with multiple medications. Finally, patients are expected to pay their bills and work with their insurance companies for processing. These are major burdens for those seeking care.

Assessment Tools and Data Collection

The question is, then, how can these demands be reduced? Fortunately, there are some promising assessment tools that can be used to help identify problem areas as well as areas in which things are working well. Table 3-1 provides a list of these tools. One tool, developed by Rima Rudd at Harvard University (Rudd and Anderson, 2006), focuses on the early visit issues described earlier (e.g., signage, forms). Rudd's instrument also asks about the availability of multilingual patient education tools and whether there are language options in the telephone system for callers. Another promising tool was developed by the Agency for Healthcare Research and Quality (AHRQ) for use in pharmacies to determine how well the pharmacy is meeting patient needs. This instrument provides guidance for performing an audit of the pharmacy, surveying both pharmacy staff and patients through focus groups.

Finally, although not a formal tool, one technique used by a number of health care facilities is to conduct a patient walk-through of the facility with diverse patients providing feedback about what is difficult and what works well.

An essential part of quality improvement is data collection and analysis. Data are necessary both to identify health disparities and to devise ways of addressing those disparities. The kinds of data that are important to collect include race, ethnicity, language, language needs, and literacy data. Health Research and Education Trust's (HRET's) Disparities Tool Kit provides guidance on collection of primary data. Data on the community served are also needed. If it is not possible or feasible to engage in primary data collection within the community, there are typically several sources of community-level data available, such as census data, school district–level data, or public health department data. Geocoding is also an option. Geocoding involves using ZIP codes and census data to map patient demographics within a specific area. Staff training is needed to ensure proper collection and analysis of data. Once the data have been collected, the next step is to use those data to identify disparities, to tailor the delivery of care to specific populations, and to describe the care being delivered.

Another source of quality improvement data can come from CAHPS.[1] These instruments are used in the annual *NHDR* to mea-

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[1] CAHPS—The family of CAHPS surveys and tools, housed at the Agency for Healthcare Research and Quality, are used in a variety of health care delivery settings to assess patient experiences of care, to provide reports on performance, and improve health care quality (AHRQ, 2008c).

sure patient experiences of care. AHRQ is refining CAHPS to assess the cultural competence and health literacy friendliness of clinical groups and practices. Additionally, the agency is focusing more specifically on areas of cultural competence and health literacy. The goal is to generate very specific information that can be used for quality improvement by a health plan or a clinician group.

Measurement on a national basis remains challenging. The *Healthy People 2010* effort, for example, includes goals for which data are not available on a national basis.

Brach concluded by presenting a list of tools that can be used to address disparities and health literacy in quality improvement. The AHRQ and Center for Medicare & Medicaid Services guides for culturally and linguistically appropriate services were developed to assist health plans with their quality improvement activities. There are two guides, one on oral language services and one addressing cultural competency. The Health Resources and Services Administration (HRSA) has developed a training curriculum (Unified Communication Training) that addresses health literacy, cultural competency, and language barriers.

Other tools include a Health Literacy Educational Kit developed by the American Medical Association, the AHRQ Health Literacy Pharmacy Tools, the HRSA Disparities Collaborative tools, and Playing It Safe with Medicines, developed by the American Academy of Family Physicians.

PATIENT-CENTEREDNESS AS AN INDICATOR OF QUALITY

Mary Catherine Beach, M.D., M.P.H.
Johns Hopkins University

Patient-centeredness, equity, quality improvement, health literacy, and cultural competence all overlap and intersect. The report *Crossing the Quality Chasm* (IOM, 2001) established six aims of quality. Integrating quality improvement, health literacy, and disparities reduction emphasizes the intersection of the patient-centered and equitable aims. When one thinks of "equitable care," one imagines a system free of racial and ethnic health disparities. But "equitable care" can also refer to a system free of disparities based on patients' levels of health literacy.

TABLE 3-1 List of Assessment Tools

Organization	Name of Resource	Websites
Assessment		
Agency for Healthcare Research and Quality	*Is Our Pharmacy Meeting Patients' Needs? Pharmacy Health Literacy Assessment Tool Users Guide*	www.ahrq.gov/qual/pharmlit/index.html
Centers for Medicare & Medicaid Services	*Culturally and Linguistically Appropriate Services Assessment*	http://www.acumentra.org/downloads/office-care/CLAS-assess-web.pdf
National Center for the Study of Adult Learning and Literacy and Health and Adult Learning and Literacy Initiative, Harvard School of Public Health	*The Health Literacy Environment of Hospitals and Health Centers. Partners for Action: Making Your Healthcare Facility Literacy-Friendly*	http://www.ncsall.net/index.php?id=1163
Communication and Training		
American Medical Association	*Health Literacy Educational Kit*	https://catalog.ama-assn.org/Catalog/product/product_detail.jsp;jsessionid=F1G31XPJSJFQNLA0MRPVX5Q?childName=&parentCategoryName=&parentCategory=&productId=prod1060004&categoryName=&prodId=&start=&parentId=
Agency for Healthcare Research and Quality	• *Strategies to Improve Communication Between Pharmacy Staff and Patients* • *How to Create a Pill Card*	• www.ahrq.gov/qual/pharmlit/pharmtrain.htm • www.ahrq.gov/qual/pillcard/pillcard.htm
Health Resources and Services Administration	*Unified Health Communication (health literacy, cultural competence, limited English proficiency)*	www.hrsa.gov/healthliteracy/training.htm
U.S. Department of Health and Human Services	*Quick Guide to Health Literacy*	http://www.health.gov/communication/literacy/default.htm

Cultural and Linguistic Appropriate Services		
Agency for Healthcare Research and Quality	• *Providing Oral Linguistic Services* • *Planning Culturally and Linguistically Appropriate Services*	• http://www.ahrq.gov/about/cods/oralling.htm • http://www.ahrq.gov/about/cods/planclas.htm
Health Resources and Services Administration	*A Provider's Guide to Quality and Culture*	http://erc.msh.org/mainpage.cfm?file=4.1.0.htm&module=provider&language=English
U.S. Department of Health and Human Service, Office of Minority Health	• *A Family Physician's Practical Guide to Culturally Competent Care* • *Health Care Language Services Implementation Guide*	• https://cccm.thinkculturalhealth.org/ • https://hclsig.thinkculturalhealth.org/user/home.rails
U.S. Department of Justice, Civil Rights Division	*Limited English Proficiency: A Federal Agency Website*	http://www.lep.gov/
Disparities		
Agency for Healthcare Research and Quality, Robert Wood Johnston Foundation, Center for Health Care Strategies, and RAND Corporation	*National Health Plan Collaborative*	http://www.chcs.org/NationalHealthPlanCollaborative/index.html
Agency for Healthcare Research and Quality	*National Healthcare Disparities Report*	• http://www.ahrq.gov/qual/qrdr07.htm, • http://nhdrnet.ahrq.gov/nhdr/jsp/nhdr.jsp
American Public Health Association	*Health Disparities Database*	http://www.apha.org/programs/disparitiesdb/
Health Research and Educational Trust	*HRET Disparities Toolkit: A Toolkit for Collecting Race, Ethnicity, and Primary Language Information from Patients*	http://www.hretdisparities.org/

Continued

TABLE 3-1 Continued

Organization	Name of Resource	Websites
Health Education Materials		
Agency for Healthcare Research and Quality	*Consumer Materials (e.g., Quick Tips – When Planning Surgery, You Can Quit Smoking)*	http://www.ahrq.gov/consumer/
American Academy of Pediatrics	*Plain Language Pediatric Education: Handouts for Common Pediatric Topics*	https://www.nfaap.org/netforum/eweb/dynamicpage.aspx?site=nf.aap.org&webcode=aapbks_productdetail&key=b26c2f09-26d3-4ba0-84b4-850d5785a9e4
American College of Physician Foundation	*Living with Diabetes: An Everyday Guide for You and Your Family*	http://foundation.acponline.org/hl/diabguide.htm
National Library of Medicine	*MedlinePlus links to easy-to-read materials*	www.nlm.nih.gov/medlineplus/easytoread/easytoread_a.html
U.S. Committee for Refugees and Immigrants	*Healthy Living Toolkit (multilingual health information)*	www.refugees.org/article.aspx?id=1851&subm=178&area=Participate
Health Literacy and Patient Safety		
Agency for Healthcare Research and Quality	*Questions Are the Answer*	www.ahrq.gov/questionsaretheanswer/index.html
American Medical Association	*Health Literacy and Patient Safety: Help Patients Understand. Reducing the Risk by Designing a Safer, Shame-free Environment*	http://www.ama-assn.org/ama1/pub/upload/mm/367/healthlitclinicians.pdf
The Joint Commission	*What Did the Doctor Say? Improving Health Literacy to Protect Patient Safety*	http://www.jointcommission.org/NR/rdonlyres/D5248B2E-E7E6-4121-8874-99C7B4888301/0/improving_health_literacy.pdf

National Patient Safety Foundation	*Partnership for Clear Health Communication*	http://www.npsf.org/pchc/
Literacy		
National Institute for Literacy	*The Adult Literacy Education Health Literacy Wiki*	http://wiki.literacytent.org/index.php/Health_Literacy
National Literacy Coalition		http://www.national-coalition-literacy.org/about.html
Reach Out and Read		http://www.reachoutandread.org/

The Evolution of the Concept of Patient-Centeredness

Patient-centeredness was first described by Balint (1969), who said that each patient "has to be understood as a unique human being." In 1984, Lipkin and colleagues described a patient-centered interview as one in which the physician approaches the patient as a unique human being with his own story to tell, clarifies the patient's concerns, understands the psychosocial dimensions of illness, and creates the basis for an ongoing relationship with the patient. This interpersonal model of patient-centeredness was the primary model for some time.

Stewart and colleagues (1986) distilled the concept of patient-centeredness down to six dimensions, the first four of which focused on communication between the patient and the physician. Stewart also incorporated two additional concepts: prevention and health promotion as important components of patient-centeredness and the notion of being aware of one's own personal limitations (Brown et al., 1986; Levenstein et al., 1986; Stewart et al., 1986).

The 1990s brought a new shift in how patient-centeredness was conceptualized to expand beyond a particular clinical encounter and towards the health care system as a whole. Sherer and colleagues (1993) defined patient-centered care as "patient care wherein institutional resources and personnel are organized around patients rather than around specialized departments." This is a broader definition that moves beyond patient–provider communication. The National Library of Medicine introduced the term *patient-centered* to its Medical Subject Headings.

Finally, in 2001, the IOM defined patient-centeredness as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (IOM, 2001).

Patient-centeredness now conceptually can include any aspect of communication between a patient and any component of the health care system (see Figure 3-3), from scheduling appointments, to access to understandable written materials, to comprehendible signage, phone calls, and e-mails. Patient-centered health care means that patient-centered interactions occur within patient-centered health care systems.

Disparities in Patient-Centeredness

There are, however, inequities in patient-centeredness. For example, at the level of the clinical encounter, data from the *2006 NHDR* (AHRQ, 2006) show that the lower the educational level, the greater

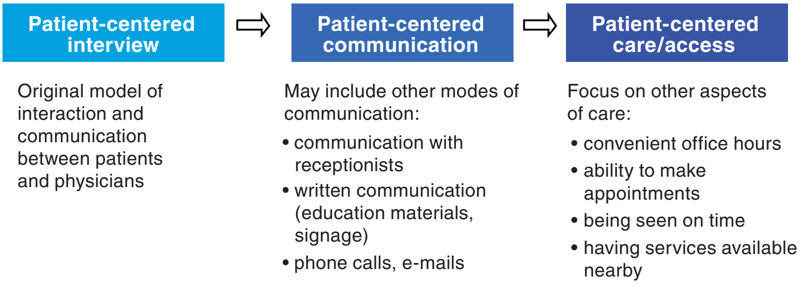

FIGURE 3-3 Through the patient's eyes: from individual interactions to systems.

the likelihood that patients say their health care provider does not listen carefully, explain things clearly, respect what the patient had to say, or spend enough time with them. These findings are even stronger for African American patients than for white patients. Data also show that there are greater communication problems for Hispanic respondents than for non-Hispanic white respondents.

At the health care system level, a study by Reschovsky and O'Malley (2008) found that physicians with a high proportion of minority patients report greater difficulty in arranging referrals to specialists, inadequate time to spend with patients, and lack of timely reporting back on their patients.

Disparities in Patient-Centeredness by Health Literacy

Disparities also exist based upon level of health literacy. Patients with lower health literacy are more likely to report worse communication with their health care providers (Schillinger et al., 2004) in the domains of general clarity, explanation of health condition, and explanation of the appropriate processes of care. Furthermore, patients with lower health literacy ask fewer questions of their physicians in observed medical encounters (Beach et al., 2006; Katz et al., 2006) and are more likely to be seen by physicians as desiring a less active role in their health care, despite the fact that these patients prefer to be just as involved as those with higher levels of health literacy (Beach et al., 2006).

Integrating Patient-Centeredness, Cultural Competence, and Health Literacy

Cultural competence at the health care system level is the ability of the system to meet the needs of diverse groups of patients. At the provider level, cultural competence is the ability of the health care provider to bridge cultural differences in order to build an effective relationship with the patient. Key features of the health care system that effectively address health literacy are the ability of the health care organization to meet the needs of patients with limited health literacy. In such a system, it is the ability to effectively communicate with all patients, regardless of level of health literacy, and learn particular strategies shown to be effective in improving care for those with limited health literacy.

A health care system that is patient-centered is one that is respectful of and responsive to individual patient needs, preferences, and values (IOM, 2001). It is important to highlight that patient-centeredness includes both cultural competence and health literacy, which ensure that health care systems and providers attend to the needs of people with different cultures, different languages, and different levels of health literacy.

Patient-Centered Quality Improvement Interventions

There are examples of quality improvement interventions designed to specifically reduce disparities and improve patient–provider communication. For example, there are three randomized controlled trials that are funded by different agencies and that are in three different disease areas: the Coached Care for Diabetes Program, funded by the Robert Wood Johnson Foundation; the Patient–Physician Partnership to Improve High Blood Pressure Medication Adherence (PPP), funded by the National Heart, Lung, and Blood Institute; and the Enhancing Communication and HIV Outcomes (ECHO), funded by AHRQ and HRSA. All three studies use patient coaching[2] to enhance communication and reduce disparities. Prior to a medical visit, patients receive between 5 and 25 minutes (depending on the study) of individualized coaching to help empower them in communications with their provider. Both the PPP and the ECHO trials also include a physician training component.

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[2] Patient coaching involves providing patients with the communication skills to talk more openly and proactively with their health care providers. This, in turn, leads to assistance in making health behavior changes and better self-management of chronic illnesses.

1. Access and Communication (9)**
2. Patient Tracking and Registry Functions (21)**
3. Care Management (20)**
4. Patient Self-Management Support (6)**
5. Electronic Prescribing (8)
6. Test Tracking (13)**
7. Referral Tracking (4)**
8. Performance Reporting and Improvement (15)**
9. Advanced Electronic Communications (4)

FIGURE 3-4 National Committee on Quality Assurance standards for the patient-centered medical home.
SOURCE: NCQA, 2008.

At a health care organizational level, the American Medical Association's (AMA's) Ethical Force Program[3] developed a performance measurement tool kit designed to assist organizations in meeting the needs of diverse patient populations. The tool kit facilitates assessment of how effectively an organization communicates with patients and targets resources for improvement. It includes materials to use in gathering feedback from the health care system, staff, and patients; a user's guide; aids for analyzing survey results; an analysis guide; and promotion materials to use in presenting survey results.

Establishing a medical home[4] is another approach to patient-centered care. As part of its physician practice connections program, the National Committee on Quality Assurance established nine standards and a scoring scheme for the patient-centered medical home (Figure 3-4). Each standard has a number of points accorded

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[3] A more complete description of the tool kit may be found at http://www.ama-assn.org/ama/pub/category/18225.html.

[4] A medical home "is not just a building, house or hospital, but a team approach to providing health care. A medical home originates in a primary health care setting that is family-centered and compassionate. A partnership develops between the family and the primary health care practitioner. Together they access all medical and nonmedical services needed by the child and family to achieve maximum potential. The medical home maintains a centralized, comprehensive record of all health-related services to promote continuity of care" (Colorado Department of Public Health and Environment, 2008).

to it. Standards with asterisks are "must pass" elements. The first standard, "Access and Communication," has relatively few points accorded to it.

Conclusions

Conceptually, patient-centered care includes attention to patients' health literacy, cultural context, and language preferences. However, considering these issues separately may emphasize their importance to patient-centered quality improvement efforts. Such efforts have the potential to reduce disparities by raising health literacy levels and targeting both the interpersonal (e.g., patient–provider) and health care system levels.

REACTION AND DISCUSSION

Ignatius Bau, J.D.
Moderator

An open discussion followed the panel's presentations. Forum and roundtable members and public audience attendees were able to ask questions of the speakers. The following section summarizes the discussion.

Business Community

A key set of partners—employers—has not been included in the discussion at this workshop, one participant stated. Employers, who are paying for health care, consider disparities an economic issue that affects only lower-income people, not recognizing how pervasive disparities are. Furthermore, she stated, transitions in employment must be considered. A patient could be in a completely culturally sensitive business unit where attention is paid to health literacy and patient-centered care, but there are no guarantees of what will happen once the patient leaves. If there is not shared recognition of the interconnectedness of disparities reduction, health literacy, and quality, the fragmented health care system will not progress. These issues need to be part of the discussion of health care reform.

Brach responded that the business community is taking some steps in recognition of the interface. One example is a tool for employers to use to make decisions about purchasing health care benefits. This tool, created by the National Business Coalition on

Health, collects information from health plans and includes a section on disparities as well as some health literacy items.

Isham responded that it is not only employers, but also the quality improvement community, who are unaware of the importance of the need to integrate cultural competence, disparities reduction, and health literacy with quality improvement efforts.

Patient Experience

The role of the patient's experience in interacting with health care organizations, physicians, and insurance companies is another factor in health literacy, one participant stated. Such interactions teach the patient a significant amount. Brach responded that there are several projects intended to use patient experiences as a mechanism for increasing health literacy. For example, the adult literacy community is working with providers to arrange field trips to provider offices so that adult learners can increase their knowledge. Another approach is to use health information content in learning-to-read activities; one study indicated that adult learners learn how to read faster when they are reading real-life health content.

Target Groups

Specific populations to consider in improving literacy include at-risk populations and geriatric patients. Wolf noted that research in health literacy has focused primarily on at-risk populations. In response to an observation that geriatric patients had not been mentioned in the exploration of issues, including the older patients who might be experiencing sensory declines or dementia, Wolf said that these populations are at very high risk for health communication difficulties. Not only do they require complex care, they are also asked to recall medical encounters, their own self-care, and what external supports are available to them.

Health Literacy Measurement and Data

Brach said that there is a problem with the way in which data on the levels of health literacy are presented. The implication of these data is that those who are at the below basic level have difficulty, but those with basic, intermediate, or proficient health literacy are able to understand and act on health information. One of the intermediate level tasks is to be able to read and understand an over-the-counter medication label. Those who score in the basic range, as well as those who are below basic, cannot perform that task. This clearly has patient safety implications.

One measures health literacy at a particular point in time, Brach continued, yet an individual's health literacy is dynamic. For example, if a patient is given a diagnosis of cancer, that patient's ability to understand and process health information plummets because of all the worries, concerns, and thoughts that crowd in. Rather than thinking about health literacy in terms of discrete intervals, one should think of health literacy as a continuum.

However, health care providers are asking their patients to be engaged in the management of their conditions, to understand and know what to do to improve their health. Thus, health literacy improvement should focus on more than individual abilities; it should also address system demands.

Models for Addressing Health Literacy, Disparities Reduction, and Quality Improvement

The need for community support has been mentioned frequently, but in the United States there does not appear to be a good understanding of how to leverage that support, one participant stated. As a researcher in Nepal and India, he found communities that had accomplished amazing things, even with no health care providers. In contrast, he said that the United States is cynical about what communities can do, and that health care providers have a jaundiced view of community involvement. Isham agreed that community support is a very complex topic with which many struggle.

Another participant stated that the workshop discussion focused primarily on complex sick patients, with little focus on health promotion and prevention. Perhaps public health methods are more relevant than the medical home for addressing issues of health literacy and health disparities.

Isham responded that the current models for a medical home are not robust enough to address the need for integration of health literacy, disparities reduction, and quality improvement. Addressing the needs of patients with relatively few medical needs or health literacy issues might be accomplished with improved information and communication techniques. Those in the middle part of the spectrum who have relatively simple, straightforward medical problems may require more coordination to ensure they understand and can manage their conditions. However, those with multiple needs and low levels of literacy require medical home models that have not yet been developed.

Moving Toward Integrating Quality Improvement, Health Literacy, and Disparities Reduction

One participant stated that the individual concepts of quality improvement, health disparities, and health literacy, as well as their integration, should be translated into the education and training of all health professionals. Wolf responded that pharmacy education is active in this area. It is necessary, however, to use a multidisciplinary approach to integrate these concepts across all levels, including pharmacy schools, medical education, and other provider education. Furthermore, other components of the health care system also require continuing education about these concepts. Currently, communication about integrating health literacy and disparities reduction into quality improvement efforts is not crossing the chasm to these other components of the health care system.

Isham responded that training future professionals is not enough. It is not sufficient to provide training and assume the difficulties will be fixed. What is critical is to determine the structures and systems that should be developed to support integration. Once this is accomplished, individuals can be trained to use these systems.

Beach agreed that training is probably only a small part of the solution. This is particularly true because there is still much to be learned about what the most effective ways of communicating are. Until there is better knowledge about the best methods for effective communication and training, it is difficult to determine what changes should be made in the already crowded health professional education curriculums.

Brach agreed that while training alone is insufficient, it is necessary. Unfortunately, students often emerge from medical school as worse communicators than when they entered because they have been trained in a very technical language and have been rewarded for the use of this language. A very encouraging development is the communication component of the physician national licensure examination.

4

Integration at the Practitioner Level

PANEL INTRODUCTION

John C. Lewin, M.D.
American College of Cardiology

Gaps in health care have been reduced. Reducing these gaps begins with measurement shining a light on behavior changes using, for example, practice guidelines, performance measures, and appropriateness-of-care measures. These are all examples of successful tools used to improve the quality of care in cardiovascular medicine. Despite advances in care delivery, however, racial and ethnic biases are still problems that must be addressed, as are access to care, cultural competency, and health literacy. The challenge is to apply lessons learned from improving quality in inpatient settings to outpatient settings to better address health care disparities.

The American College of Cardiology (ACC), a 37,000-member organization, has taken a great interest in the issues of health disparities and health literacy. Fifty-four percent of its members have electronic health records in their offices, a necessary tool for the application of evidence-based clinical decision making. To assist in measuring performance, the ACC has established the National Cardiovascular Data Registry. The ACC is also creating a website for patients in both English and Spanish that will explain diagnoses and talk about medications and their side effects.

Despite great progress in addressing disparities, research has shown that bias is still a problem, as is lack of cultural competency and low health literacy. For example, in coronary artery disease there are disturbing disparities based on race and gender in terms of referrals and treatment. The following panel was designed to provide us with input on ways to improve quality at the provider level by addressing health disparities and health literacy issues.

HEALTH PLAN LEVEL

Grace H. Ting, M.H.A.
WellPoint

The convergence of quality improvement, reducing health disparities, and improving health literacy is the focus of a pilot program at WellPoint, a health plan covering 35 million members. The program gathers data for the purpose of developing profiles of patients with particular conditions, such as diabetes. Data can also help researchers identify factors that could be associated with patient behaviors, such as adherence to treatment protocols, said Grace Ting of WellPoint.

Therefore, the first step of the program is collecting valid data, as discussed by previous speakers. Because collecting this type of data on individual members is often expensive and time consuming, WellPoint developed its Proxy Methodology to identify members of different racial and ethnic groups that may benefit from more focused quality improvement interventions. This methodology combines geocoding and name analysis to develop race and ethnicity estimates that can be rolled up to characterize health care quality improvement needs at a variety of levels, including the regional level, health plan level, and provider practice group level. WellPoint has also engaged physician groups in quality improvement initiatives to address disparities.

Questions have been raised about whether proxy data are good enough for analyses and application in quality programs. As can be seen from Table 4-1, indirect methods have a high degree of accuracy when comparing population groups. WellPoint has conducted extensive testing on the validity of proxy data by comparing internal self-reported data with data generated using the Proxy Methodology.

WellPoint has also conducted some health disparities market research to develop a profile of "adherent" diabetic patients who take proactive care of their health. In the first phase of this three-phased approach, focus groups of adherent individuals were con-

TABLE 4-1 Aggregate Demographics—Predicted Versus Reported

Approach N = 192,096	Hispanic (%)	Asian (%)	Black (%)	White/ Other (%)
Surname only	46.1	6.6	7.1	40.2
Geocoding only	41.3	7.9	11.9	39.0
WellPoint model	52.1	7.9	14.7	25.3
Member self-reported data	52.0	8.0	14.8	25.2

ducted to discover factors (e.g., behavioral, situational, psychological) that facilitate proactive action for health management on the part of members. One of the findings was that low health literacy can be an indicator of poor communication between patient and provider for such reasons as patients not being told how to care for their conditions or being afraid to ask questions.

In phase two, based on the results of the focus groups, interventions and materials were developed and tested with focus groups of "nonadherent" individuals. The final phase developed pilot deployment recommendations, including proposed metrics to measure the success of these enhancements.

WellPoint's pilot program is in the process of making systematic changes in three specific areas. First, disease management programs are being enhanced to be more culturally and linguistically specific, including recognizing patients' spirituality, family, and community. Through the development of new materials to disseminate information, WellPoint hopes to address fears by producing improved, individually relevant targeted information. Second, benefit structures are undergoing changes to reduce the financial burden of care. For example, to help diabetic patients with their prevention needs, WellPoint may cover glucometers or reduce patient copays for insulin. Third, clinical staff is to be better matched to patient populations, both culturally and linguistically. Significant training efforts in terms of culturally sensitive scripts and webpages for use by all staff (e.g., physicians, nurses, and administrative staff) are under way when treating specific populations such as the Latino and African American populations. Efforts will need to be made to explore the best ways to communicate with target audiences such as development of DVDs, videos, and media entertainment to promote lifestyle changes (e.g., better diet) and provide tips on living with health conditions.

Ting concluded by saying that a fine line exists when promoting culturally and linguistically relevant materials. One could be perceived as stereotyping or racially profiling members. Therefore, transparency and honesty are critical in the development of such programs.

AMBULATORY CARE LEVEL

Thomas D. Sequist, M.D., M.P.H.
Harvard Vanguard

Outpatient providers can combine their intimate knowledge of patients and understanding of the health care system in unique ways to address disparities in care. Harvard Vanguard Medical Associates (HVMA) is an integrated delivery system with 14 health centers and approximately 130 primary care physicians who care for 300,000 adult patients, of whom 15,000 are diagnosed with diabetes. Beginning in the mid-1990s, HVMA began to implement a new model to improve the delivery of diabetes care. This first included implementing an electronic health record and creating point-of-care electronic decision support ("reminders") for physicians. This was followed by developing a more robust electronic diabetes data registry that allowed tracking of all patients with diabetes and enabled identification and outreach to patients overdue for recommended care in the form of automated mailings.

Recognizing that clinical decision support tools and patient mailings alone were insufficient to achieve good diabetes care, the next phase of improvement focused on restructuring chronic care delivery. This led to changes in the HVMA primary care system that identified new roles for all care team members, including nurse practitioners, nurses, and medical assistants, and additional training in such areas as health promotion and patient engagement. Diabetes dashboard reports, containing a list of each clinician's patients with diabetes, were provided to each physician on a quarterly basis. These reports contained key clinical information including recent laboratory test results, blood pressure measurements, medications, and recent referrals. Such information was used by clinical care teams to develop treatment plans both between and during office visits.

With these changes, the quality of diabetes care improved and the racial disparity in care processes (e.g., annual cholesterol testing) were eliminated over time. Patients also realized better intermediate outcomes following these interventions, with more patients achieving lower levels of cholesterol. However, a significant gap in rates of cholesterol control between white and black patients unfortunately persisted. One potential reason for this gap is a persistent difference in prescribing behaviors of physicians, with black patients remaining less likely than whites to be prescribed statins.[1]

It is important to note that the focus of these interventions within the HVMA primary care system was not to improve minority care or to reduce disparities—it was to improve the quality of care for patients with chronic conditions, exemplifying the positive impact quality improvement interventions can have on disparities. However, such nontargeted interventions are not a perfect solution, as demonstrated by the persistent disparities described above.

A critical byproduct of quality improvement interventions is their potential impact on racial disparities. Recognition of this has led to the question of what role ambulatory care can have on reducing disparities. Outpatient physicians can play an active role in eliminating disparities by addressing patients' individual health care needs and identifying barriers within the health care system to better guide patients toward improved health outcomes. A central advantage to the outpatient physicians' roles is the direct involvement in clinical care and the trust developed through long-lasting patient–provider relationships. The trust engendered in patient–provider relationships can help improve patient experiences of care, which has implications for improved adherence and quality of care among minority patients.

To move the field forward, Sequist recommended increased collection of race and ethnicity data, improving physician awareness of the importance of disparities within their local health care environment, and developing targeted interventions to address disparities. In terms of data collection, 75 percent of medical groups currently do not collect race or ethnicity data. Among the 25 percent of groups collecting these data, the completeness and accuracy of the data are not clear. Echoing Ting's point, 80 to 90 percent of patients are comfortable with the collection of race/ethnicity data, but health care providers must be honest and foster transparency about how the data will be used.

Improving physician awareness is necessary to move the field forward because many physicians do not recognize the importance of disparities, particularly within their local health care environ-

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[1] Statins are medications to control cholesterol.

ment, such as within their own panel of patients. This failure to recognize potential biases in health care delivery and ultimately disparities in health outcomes at the local level persists, despite the fact that disparities have been shown to be fairly evenly distributed throughout the entire system. A potentially useful strategy might be to make clinicians more aware of their performance through nonpublic performance reporting of racial disparities. Health care systems should explore training in cultural competency for clinicians to raise awareness of disparities and ultimately improve communication with minority patients regarding the management of their chronic condition (e.g., choosing healthy foods, getting proper exercise, and controlling stress).

Finally, the effect on disparities of increasingly popular policies to improve quality of care must be considered. In particular, pay for performance and public reporting may both have considerable unintended consequences, potentially worsening disparities. Policies should be designed in ways that actually alleviate disparities, not augment them, Sequist concluded.

HOSPITAL LEVEL

Michael P. Pignone, M.D., M.P.H.
University of North Carolina

People with low health literacy skills are at risk for a number of adverse health outcomes (Dewalt et al., 2004a; Pignone et al., 2005). The relationship between literacy and adverse health outcomes, however, is complex. Some aspects of preventive care, for example, do not differ by literacy status, indicating that more research is needed to identify the mechanisms by which literacy leads to adverse health outcomes.

As others have discussed, health care is only one of the factors that affect health. Patients with greater access to resources such as higher literacy, greater socioeconomic status, and health insurance coverage may find it easier to avoid poor health outcomes, despite good or bad quality of care. More vulnerable people with fewer resources are at greater risk of receiving poor care and having bad outcomes.

Systems are currently suboptimally organized to deliver high quality of care, offering opportunities for improvement. Organized care can reduce literacy-related health disparities. Appropriate interventions to change how health care is organized can make a difference in health outcomes.

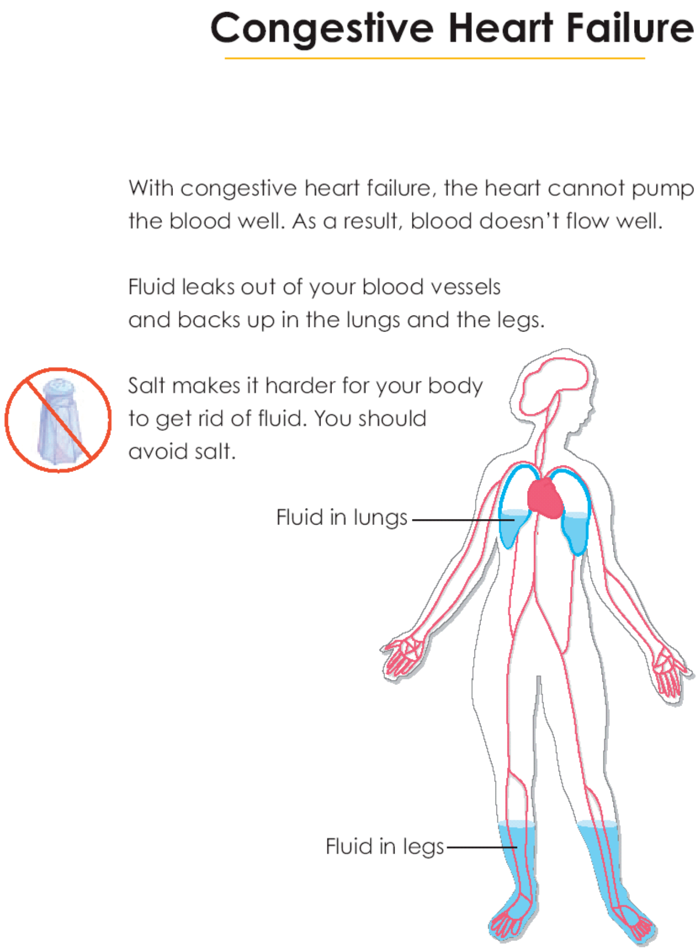
One example is an intervention to improve care for patients with congestive heart failure (CHF). CHF affects 5 million Americans and is the leading cause of hospitalizations among the elderly. Of those hospitalized, 25 to 50 percent are readmitted within 3 to 6 months. Half of CHF admissions are thought to be preventable with good medical care and good self-care. However, good self-care is not well taught.

Currently, patients are often overloaded with information about how to live with CHF; guidelines exist for approximately 25 best practices (Grady et al., 2000). As a result, patients do not necessarily know how best to manage their health care. Pignone and colleague Darren DeWalt sought to improve teaching of CHF self-care. After reviewing the literature, reflecting on clinical experiences, and conferring with patients, they developed materials that boil down to seven guidelines based upon literature review and clinical experience (DeWalt et al., 2004b). They found that providers often use a traditional biological model, but that patients need teaching in a different, more patient-centered manner. Thus, materials should be developed that do not overemphasize anatomy and pathophysiology at the expense of focusing on symptoms and impact on functional status (see Figure 4-1).

Another example of their educational materials is a visual guide for controlling fluid balance. Many patients are never told what their optimal weight should be in terms of fluid balance. Patients often receive general verbal instructions that "if your weight goes up or down 3 pounds, either double or halve your medication." This type of instruction is too abstract for many patients to follow. To help patients better understand directions, visual guides such as the one in Figure 4-2 were developed.

These materials must be complemented with training so that patients can use the tools and manage their conditions on a daily basis. A randomized trial of these interventions was conducted with 130 patients. The incidence rate for hospitalizations and death decreased by almost 40 percent for those receiving the self-care program as compared to those who received a standard heart failure pamphlet alone (DeWalt et al., 2004b). The reduction in hospitalizations was even greater for those with low literacy levels compared to those with adequate literacy.

These examples suggest that interventions may differentially help groups of people with low levels of literacy and may reduce literacy-related disparities. If this notion is accepted, three actions must take place. First, the organizational structure of health care must be changed because most places are too decentralized and



Congestive Heart Failure

With congestive heart failure, the heart cannot pump the blood well. As a result, blood doesn't flow well.

Fluid leaks out of your blood vessels and backs up in the lungs and the legs.

Salt makes it harder for your body to get rid of fluid. You should avoid salt.

FIGURE 4-1 Example of easily understandable, patient-centered materials.

lack a strong focus on clinical quality improvement, thereby limiting leadership and clinicians' abilities to widely enforce quality improvement initiatives. Compounding this is the fact that most health care leaders lack experience in implementing quality improvement interventions. Second, the financing systems must change to compensate patients for nonphysician encounters. Third, political advocacy should be cultivated to organize low-literacy patients to garner attention to their needs.

The infrastructure for implementing health care quality improvement exists primarily in inpatient settings. Hence, interventions are

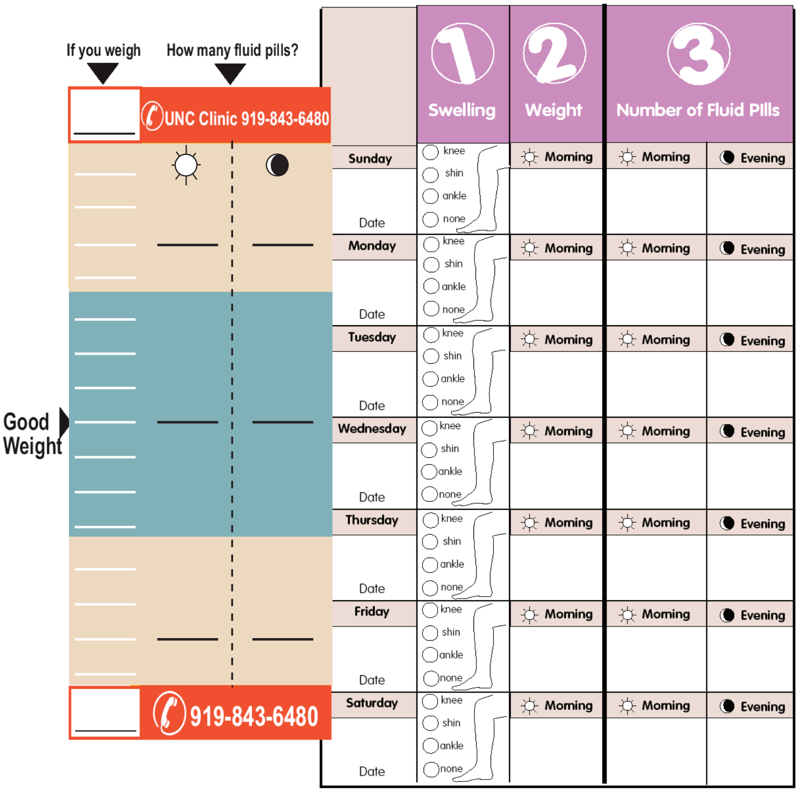


FIGURE 4-2 Visual guides for medication use.

less common in outpatient settings, which are generally better environments to train patients in self-care techniques. The health care system should be viewed as a full system working in both settings, as opposed to separate inpatient and outpatient systems, thus facilitating a more systemic focus on care transitions.

For the future, Pignone concluded, universal recognition of barriers to high-quality care is critical and requires the involvement of institutional leadership, which is currently lacking in many places. Support from institutional leaders would facilitate routine tracking of process and outcomes measures, as well as integration of system-based approaches. To support institutional commitment, purchasers and payers must work together to reorganize the reimbursement system.

REACTION PANEL

Nicole Lurie, M.D., M.S.P.H.
RAND Corporation

On the basis of experiences with the National Health Plan Disparities Collaborative,[2] action must take place now. It is often understood that measurement is central to change, but while many providers have started addressing disparities and literacy, many others have not yet begun. Methods are available for collecting data in relatively quick and inexpensive ways—for example, using indirect measures such as what is done by WellPoint with its Proxy Methodology for identifying ethnicity. Similar methods for health literacy became available in the summer of 2008 from RAND and American Institutes for Research. These data collection efforts allow for collection of critically needed data that can be used to identify those people needing special attention.

In environments with limited resources, simple tools may be used to identify populations in need. For example, mapping is a useful tool to identify disparities, gaps in literacy, and differences in quality measures and should be used to identify clusters of "hot-spots" where patients are not receiving appropriate care. In this way, interventions with translations into Spanish, for example, would be implemented only in geographic areas with high Spanish-speaking populations, as opposed to the entire country.

Finally, Lurie reinforced the need for collaboration and shared responsibility. Given the high rates of comorbidities in the United States, diseases can no longer be approached in isolation from each other. Sets of interventions that support care, improve literacy, and address disparities after visits with providers need to be developed for homes, workplaces, and schools. Large numbers of uninsured people in a community negatively affect the entire community because expectations for the community fall, resulting in worse care. Efforts must be put in place to engage stakeholders to become part of the solution.

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[2] The National Health Plan Disparities Collaborative consists of 11 health plans, both national and regional, from around the country.

Marshall Chin, M.D., M.P.H., F.A.C.P.
University of Chicago

Marshall Chin of the University of Chicago and a member of the Forum on the Science of Health Care Quality Improvement and Implementation responded to the panel by making six points based on his experiences with community health care and the Robert Wood Johnson Foundation's Finding Answers[3] program.

First, he noted that all three panel members said cultural competency training for health care providers can help improve knowledge and skills, but this alone is not enough to change outcomes. Despite the fact that multifactorial interventions tend to be effective, health care providers are not taught in this way. Quality improvement and systems thinking are concepts often missing from health professional curricula. Even when present, this training is divorced from cultural competency and literacy training in schools.

Second, culturally tailored quality improvement interventions are more effective than general quality improvement interventions, as noted by Ting and Sequist. This conclusion was also found in the Finding Answers program, where being respectful of patients' health beliefs and behaviors—even having culturally appropriate artwork—led to the building of trust between patients and providers, critical in efforts to reduce disparities.

Third, the importance of context, a concept central to the Forum on the Science of Health Care Quality Improvement and Implementation's discussions, must also be addressed. Quality improvement interventions to reduce disparities should be individualized to specific contexts, such as different populations, settings, and financial situations. Few articles in the current literature describe interventions to bridge disparities in different contexts, identifying an area where more research is needed.

Fourth, health care systems must understand the need for consumer engagement and become more involved at the community level. The rise of consumer engagement has two levels: Level one involves the decisions made by purchasers, employers, and large coalitions, while level two concerns individual communities and patients, and the work of people who bridge to the health care system such as community health workers. These are critical com-

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[3] Finding Answers: Disparities Research for Change is a Robert Wood Johnson Foundation program that "seeks to improve the quality of health care provided to patients from racial and ethnic backgrounds likely to experience disparities" (RWJF, 2008).

ponents because they address the continuum of factors impacting health outcomes.

Fifth, chronic care management requires new models of reimbursement. Given the rise of chronic care, the reduced number of generalists, and the growing evidence of the need for primary care, the patient-centered medical home is a striking concept. The medical home may soon be used to address reimbursement issues, such as payment for care coordination, and must be considered from the perspectives of both society and providers.

Finally, pay-for-performance programs, as discussed by Sequist, should be specifically designed to reduce racial and ethnic disparities. In the general literature, few articles focus on the effect of pay-for-performance programs on health disparities, stemming from the fact that only a small number of pay-for-performance programs are being designed with that focus.

Chin concluded that while all six points reflect critical issues, none can be addressed independently because they highlight where bridges to different areas need to be made. For example, reforming training of health care providers to include quality improvement and systems builds a bridge to the field of professional education. These bridges must be built to strengthen the health care system and achieve the goal of integrating health literacy, disparities reduction, and quality improvement.

Steve Somers, Ph.D.
Center for Health Care Strategies

Medicaid is a leverage point for change with 55 million beneficiaries and a budget of $360 billion. In this Medicaid population, 55 percent of the nonelderly are members of racially and ethnically diverse groups, thereby presenting a great opportunity to reduce disparities. It would be interesting to obtain data on health literacy levels within the Medicaid population.

To improve quality and reduce costs, stakeholders must be convinced that these issues are important, which requires making a business case for quality. To make that business case, it is necessary to identify and stratify the populations (both beneficiaries and organizations) for whom the greatest benefit can be obtained. Interventions should then be targeted at specific groups; one large group is Medicaid beneficiaries.

Opportunities for improvement are particularly significant in the Medicaid population, where 65 percent of beneficiaries are in managed care plans and large numbers live with chronic illnesses and comorbidities. Data on Medicaid beneficiaries are measured by individual states and are of variable quality. The Center for Health Care Strategies (CHCS) is working with some states to identify primary care practice sites that serve racially and ethnically diverse beneficiaries. For example, in Detroit, Michigan, 50 percent of Medicaid beneficiaries are treated by practices run by only one or two doctors; 70 percent of Medicaid beneficiaries in Arkansas are treated by solo practitioners. Data should be gathered on these populations and be used to improve their care, with the goal of better health.

Somers concluded with the hope that CHCS's programs in states with high concentrations of diverse populations and often poor quality scores could stimulate cross-stakeholder and cross-payer collaborations (i.e., state and health plans work together with providers to improve quality, reduce disparities, and address health literacy).

DISCUSSION

Resource Management

Decisions on the most effective use of resources must be made using both a systems approach (allocation of resources based on likelihood of doing the most good) and a universal precautions approach (provision of resources to all potential users); it is not an either/or situation, Lurie said. Some situations will involve universal precautions, and others will require specific targeting. Even with universal precautions, available resources are often not enough, as people and groups tend to need more resources than they receive.

The financial imperative and the bottom line cannot be ignored, Lurie said. Somers noted in agreement that often the business case for quality must be the starting point, beginning with high-need, high-cost populations. A spillover benefit will accrue to those organizations and populations for which the business case is less strong because the degrees of improvement are fewer. Many health literacy interventions—for example, in the treatment of heart disease—have produced cost savings and benefits to both low-literacy patients and high-literacy patients, but to varying degrees.

A balance must be found between the seemingly contradictory concepts of a one-size-fits-all approach to the general population based on evidence-based standards and individualization of care to specific needs and circumstances, Chin said.

Business Case

A question was asked about the necessity of having a return on investment for health care interventions, as some improvements might not be accompanied by a positive return on investment. Somers stated that it is necessary to start moving in this area and that the business case for quality is not solely measured in monetary terms; issues such as reputation and quality of life are also critical. Making the financial case for at least some situations is necessary, however. Lewin noted that the business case for structural improvement must be made (e.g., data collection, registries, information technology), stating that these improvements provide the basis for further improvements (e.g., public reporting).

Capacity Building

One questioner noted that the capacity to improve health literacy at the societal level needs to be built, but asked how care should be delivered for "resourced" populations. Most efforts focus on under-resourced populations and therefore do not approach the issue from a population level. Lurie responded that every encounter and experience ought to be an opportunity to build health literacy, recognizing that many providers currently do not believe that building health literacy is part of their responsibilities. The burden of developing health literacy, however, should not be placed solely on providers but also on the public health system, driven by the government in a reinforcing relationship.

The adult education community provides critical examples for building literacy skills, Pignone said.

Medical Home

In response to a question of whether the concept of medical homes should begin with physicians or potentially be viewed with a focus on nurses, community health workers, or patient navigators, Chin responded that many benefits exist to having a comprehensive, multidisciplinary team focus. The effectiveness of nurse-led systems and team interventions is a common theme found in disparities intervention literature.

5

Breakout Groups

Workshop attendees were asked to split into three breakout groups: (1) ambulatory care, (2) health plans, and (3) hospitals. Each group was assigned a moderator/discussion leader to summarize the discussion and report this content back to the larger group. This chapter summarizes the reports from the three breakout groups. The groups were asked to talk about identifying best practices and determining what needs to be done in the future in terms of changing and improving the current system.

AMBULATORY CARE

Carolyn Clancy, M.D.
Agency for Healthcare Research and Quality

Best Practices

In addressing best practices, the group discussed ideas such as using "asthma educators." These are professionals who tailor instructions for use by asthma patients. David Olds at the University of Colorado has created a similar intervention using public health nurses as home visitors with new mothers of young infants.[1]

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[1] Home visitors are typically nurses who are trained to work with new mothers in the home to assist with child-rearing strategies, maximizing child health outcomes, and maternal life course development options such as finding work or planning future pregnancies.

Several projects originating in health departments were also described. First, in Phoenix, Arizona, a diabetes intervention focused on training pharmacists because they were seen as a point of entry for patients into the health care system.

California has several interesting projects as well. The state has had success in increasing the rates of mammography for breast cancer screening in lower-income women. In fact, low-income women in California actually have higher screening rates than other women because of the resources spent on this effort.

The issue of targeted data was also a theme for discussion regarding best practices. Targeted data can serve as a kind of compass or GPS system to let one know if an intervention is working or if there are problems. In this way, these interventions are data-driven public health policies. In California, for example, health department personnel used such data to drive dramatic improvements in mammogram rates for poor women.

Cultural Competency

Clancy's breakout group also discussed the concept of being a member of a team. The team concept itself requires knowledge of and experience with cross-cultural communication.

Lewin described a program at an Indian Health System care facility that required physicians to go out into the community to where people live. In this way, they had to travel to the reservation in order to see the environment in which people lived and the circumstances of their lives.

Quality Improvement

Several tensions within the quality improvement community were discussed. First, can quality improvement be attained "one disease at a time"? Second, there is the tension between disease-focused efforts and person-focused efforts. And finally, what are the potential spillover effects from any quality improvement effects?

HEALTH PLANS

Alicia Dixon, M.P.H.
The California Endowment

Collecting and Using Data

Much of the discussion in the health plan group focused on California Senate Bill 853, a bill that would require health plans to systematically collect and report race, ethnicity, and language data. The widespread perception was that this would be very costly to implement. Dixon said that the group believed that the data collected should be standardized, and that there should be a shared baseline standard so that plans can customize their data collection in order to meet the needs of their patient population as well as the requirements of their system.

Health information tools and data systems already available were discussed. Three examples mentioned were the Health Information Exchange,[2] CAHPS,[3] and the Healthcare Effectiveness Data and Information Set (HEDIS).[4] The group discussed the pros and cons of each of these tools as they relate to doing a better, more systematic job with data collection.

The group suggested that a patient medical record be created during the fetal development period so that data can then be collected in a universal way, without variations across state lines. However, such an approach would raise major concerns about privacy and individual consent.

One source of tension, however, is that ultimately, patients do not want to be stereotyped based on the demographic information collected in health plan information systems. Understanding the diversity and cultural background of the patients being served is valuable; there is greater opportunity to provide higher-quality care.

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[2] Health Information Exchange—Health information exchanges provide the ability to share clinical information between organizations within regions or communities. Regional health information organizations are formal organizations that conduct health information exchanges.

[3] CAHPS—The family of CAHPS surveys and tools, housed at the Agency for Healthcare Research and Quality, are used in a variety of health care delivery settings to assess patient experiences of care, to provide reports on performance, as well as to improve health care quality (AHRQ, 2008c).

[4] HEDIS—The Healthcare Effectiveness Data and Information Set, developed by the National Committee on Quality Assurance, is a tool used by health plans to measure a specified set of health care metrics.

Quality Improvement, Cultural Competency, and Health Literacy

The discussion about quality improvement, cultural competency, and health literacy focused on two specific examples. The first example was a medication titration study with diabetes patients. A curriculum, developed at a sixth-grade reading level, teaches patients how to self-determine the level of medication needed to take better care of themselves. The second example was a hospital-based project where diabetes patients were provided with health coaches and nurses to support them in their care.

Both of these programs are examples of projects that attempt to integrate health literacy and cultural competency into quality improvement. However, there are significant barriers to taking interventions such as these to scale. Among the barriers discussed were labor challenges, different models of care across different health care systems, and scope of practice.

Patient-Centeredness

Patient-centeredness was also discussed. Expecting a patient who works to make an office visit during the workday is not patient-centered. This is one of the tensions of making systems more patient-centered. Should the system as it exists be more accommodating, or should the system assess the patients' needs? The latter is a higher bar for patient-centeredness.

HOSPITALS

Thomas Boat, M.D.
Cincinnati Children's Hospital Medical Center

Quality Improvement Efforts

The discussion began with the recognition that hospitals are complex places, which means that making changes within the hospital system is inherently difficult. Although every hospital has a quality improvement program, health disparities and health literacy are issues that rarely are recognized as important within the hospital. Thus, the group noted the need to get the attention of the quality improvement leadership and the hospital management team.

No solutions were proposed, although participants saw the workshop itself as a positive and important effort. One potential outcome might be courses in health literacy for hospital CEOs.

Given the complexity of the hospital environment, it is important to focus on changes that are doable and actionable. Additionally, it is important to show successes with quality improvement projects because success brings attention, which in turn brings more opportunities for success down the line. An example of a program that is likely to be successful is one focusing on quality improvement for interpreters in hospitals. Although this is not a big project, it is a doable project. Similarly, a change as simple as having a pharmacy in the hospital can make it easier for the patient to make the connection between the written prescription and getting the information needed to take the medication in the prescribed way.

Hospital–Community Communication

Also discussed was the need for an interface between the hospital and community programs. Although extremely important, this is a gap for most communities. When approached, communities typically do not want to work with hospitals because the perception is that the hospital will just take over and tell them what to do.

So how is the dialogue initiated? Although the group had different perspectives on this, it was recognized that both parties need to feel responsible for making the linkage and figuring out the roles and responsibilities of each. Clearly, programs such as the home visitor model, the health promoter intervention,[5] and transitional care providers[6] can all amplify what it is that the hospitals do.

Communication within the hospital system was also discussed. Recognizing that physicians are generally not the best communicators, at least a couple of groups within the hospital should be trained in communication skills (e.g., social workers and psychologists) and serve as resources and models. Besides determining *who* should do the communicating, the team also needs to decide *what* will be communicated and how.

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[5] The health promoter intervention model involves community members whose work complements the work of the health care team with actions and interventions such as encouraging behavior change and delivering relevant information to community members.

[6] Transitional care providers ensure the coordination and continuity of health care during the movement between health care practitioners and settings as a patient's condition and care needs change because of a chronic or acute illness.

Collecting and Using Data

The issue of data and the use of these data were again discussed. One important issue is for the hospital to determine who is the target population being served. Should the target be the entire patient population, or should data be used to separate out the at-risk population that might need more attention?

It is anticipated that in the future there will be individual tailoring around genetic information and environmental exposure information. The group also saw value in tailoring around psychosocial issues as well. In other words, the goal is to understand each patient as he comes into the hospital system—not only his needs and preferences, but his individual biological, social, and emotional responses as well.

GENERAL DISCUSSION

Marshall Chin, M.D., M.P.H.
Moderator

The discussion began by asking in particular that participants focus on what should happen next to continue improvement in the areas discussed during the workshop.

A participant stated that there actually has been progress in the area of developing clinical *process* measures such as access to health screenings. This is an area where disparities have been eliminated in many instances. For example, when considering lipid screening for diabetic patients, breast cancer screening, or colonoscopy screening, there is no evidence of disparities. What is not known, however, is whether there are disparities with regards to the *outcomes.* Posing a question to the group, the participant asked if anything might be transferable from eliminating the gap with process measures to eliminating disparities in outcomes.

Pignone responded by pointing out that many of the process measures involve ordering tests of varying degrees of complexity. Getting blood drawn, for example, is considerably less complex than getting a patient to have a colonoscopy. Harder still is negotiating a care plan that involves self-care and self-adherence.

Pignone also acknowledged that the system is especially good with care that involves profit to the health care delivery system. For services that are not well compensated in the current care system and require complex interaction and greater levels of patient-centeredness, there is less likelihood of good care.

Another participant noted that when considering process versus outcome measures, there is little effort to document the interventions themselves. It was suggested that documenting the intervention should lead to a better idea of what contributed to the outcomes. In other words, there is a need to *standardize* interventions so that it is clear what occurred in order to bring about change.

One audience member commented that from her perspective, the first step is to understand what outcomes are desired, before processes needed to reach those outcomes can be determined. The discussion continued with agreement that interventions are not well documented in the literature, making it difficult to replicate them.

Isham brought up the data issue again by emphasizing that standards are important for collecting data regarding race/ethnicity and health literacy and that these data should be collected at a national level. He suggested that the Institute of Medicine (IOM) acquire funding to study this issue. He also discussed the lack of standards and consistency across states in the collection of Medicaid data. This variation in programs makes it difficult to work with private payers. Therefore, another problem is how to encourage more consistency and standardization, not only within the government, but with private and public payers as well.

Paul O'Neill, co-chair of the Forum on the Science of Health Care Quality Improvement and Implementation, stated that there is a study showing huge economic value to a system using inter-operational standard electronic records. Given the growing scarcity of resources in American society, it is unfortunate that leaders have not acted on this. Again, it was suggested that the IOM encourage this, in terms of equity, equality, and ethnicity, and make a call for action on this issue.

The topic of a disease registry tool was discussed. This tool allows a physician or a health care team to review any number of patients who meet defined criteria (defined generally by their disease, such as diabetes). One participant wondered if this same tool could be used to track patients in terms of their risk for poor health literacy. It was suggested that this was a risk factor that should be followed proactively by a physician or health care team.

It was noted by one participant that with 2009 approaching and a pending change in the administration, there will be a great deal of interest in these issues. It is not enough, however, to focus solely on the electronic record. What also needs to be clarified is what the respective roles are within a health care team and who would have access to electronic data.

It was reiterated that a major challenge in this field is finding support to get this work done. People who live in disadvantaged areas have a greater likelihood for bad outcomes in spite of an intervention; providers and the system need to be made aware so that there is a greater likelihood of *positive* outcomes.

The role of context was again emphasized in terms of implementing quality improvement, health literacy, and health disparities reduction efforts. Context includes the health care system but also the community.

Multiple demands for a more patient-centered health care system are being placed on health care providers, nurses, physicians, and others providing care. But to really transform the system, it is not enough to "work around the edges"; rather, what is needed is to turn the health care system "upside down" so that it really is a patient-centered system.

In closing, it was noted that as a starting point, people need assistance in finding their way through the health care system. Although there are many other reasons to improve health literacy, this is the basic foundation for improvement efforts.

6

Policy Issues of Integration

DATA AND MEASUREMENT

Romana Hasnain-Wynia, Ph.D.
Northwestern University,
Feinberg School of Medicine

Communication in an effective, patient-centered manner is at the heart of providing high-quality health care. However, many challenges exist to achieving high quality of care for low-literacy patients. First, few measures are available for either patient-centeredness or equity in health care, as there is currently little incentive to use such measures. Second, health care organizations do not collect data about patients' race, ethnicity, and primary language in patient-reported processes. Such data would allow for the assessment of whether implemented initiatives indeed made changes for the better. A third challenge is recognizing that providing patient-centered care within institutions is critical, but not sufficient. Fourth, health literacy is part of a larger, more complex component of providing effective communication with all populations. Many publications have demonstrated that low-literacy racial and ethnic minorities and patients with limited English proficiency have poor outcomes. The system must move beyond documenting disparities toward actions to eliminate them.

As Lurie discussed, when deciding how best to use resources, it is important to use what is available and not wait for the ideal.

Current measures of equity are stratified measures of clinical effectiveness linked to race and ethnicity, limited English proficiency, and literacy. Challenges to developing better equity measures begin at the organizational level. Although 80 percent of hospitals and 45 percent of physician practices reported collecting patient race, ethnicity, and language data, less than 20 percent use data for quality improvement. It simply is not part of the culture of most providers. Little incentive exists to stratify data, which would allow data to be used to support changes. Development of equity measures would be greatly helped by creating a uniform method for collecting race, ethnicity, and primary language data at the health care organization level, coupled with providing incentives for organizations to do so.

The ideal measures of equity are measures of patient-centeredness. Current patient-centered measures are self-reports of satisfaction, such as those used in CAHPS. These measures are important to capture, but there is reluctance to place weight on them as true measures of patient-centeredness because of their weak linkages to outcomes and the potential unintended consequences to providing care of reporting these data. To move beyond patient experiences of care, structural measures are needed, such as whether organizations know and understand their patient populations. Organizations need to be responsible for implementing ways to assess equity and disparities, suggesting that incentives to measure patient-centeredness must be developed.

Health disparities are driven by a combination of who you are and where you get your care. Studies have shown that the magnitude of disparities decreases substantially across specific quality measures when controlling for differences in care between hospitals, suggesting that where minority patients receive their care is a driver of disparities in health care. Understanding the balance between these drivers of disparities (who you are versus where you get your care) is critical when determining where interventions should be targeted.

Policies to support elimination of disparities and improved patient communication should also be developed further. The potential for performance incentives to improve quality but also to augment the disparities gap must be recognized. It is important to focus on patient-centered care to reduce disparities nationally by targeting interventions both within hospitals as well as by developing policies that improve care across hospitals and other health care settings, Hasnain-Wynia concluded.

NATIONAL PERSPECTIVE

Paul Schyve, M.D.
The Joint Commission

The Joint Commission's mission and focus is quality and safety of patient care. The Joint Commission, which accredits approximately 15,000 providers on the basis of national standards, has had standards in place for respecting cultural differences for many years. These standards have increasingly included standards on cultural competence, linguistic competence, and health literacy. Currently, the patient's primary language and barriers to communication are required to be recorded for every patient. A movement also exists to expand what is currently thought of as "culture" to include the cultures associated with visual, hearing, mobility, and cognitive disabilities. Addressing cultural differences in communication is critical to providing high-quality care, as the frequency and magnitude of adverse events increase with poor communication.

Figure 6-1 shows the relationship between providing high-quality safe care to the patient at the "sharp end" and the organizational culture and infrastructure at the "blunt end." While patient-

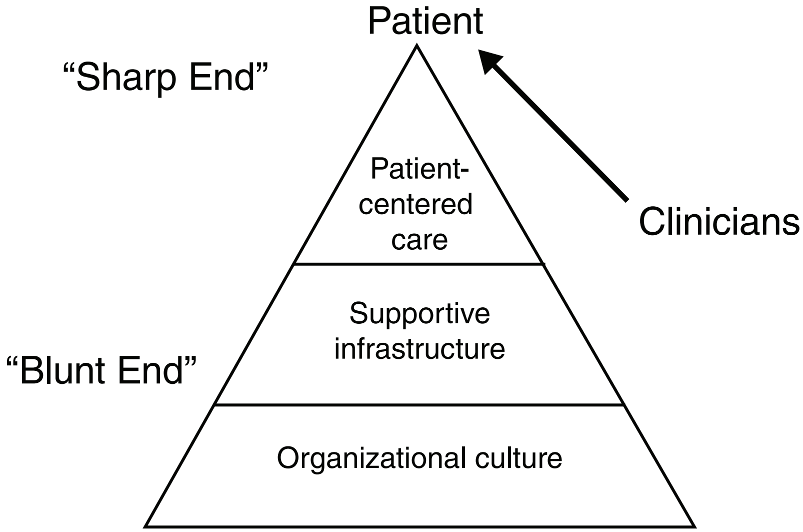

FIGURE 6-1 Providing high-quality safe care.

centered care occurs between clinicians and patients, it relies on the organization's supportive infrastructure, and the infrastructure (i.e., resources, policies, and procedures) is enabled, created, and sustained by the organization's culture. The ultimate goal—to provide patient-centered care for each patient—can be achieved only if the infrastructure and culture are in place to enable providers to do so. For example, it is difficult for English-speaking clinicians to communicate with Spanish-speaking patients if interpretive services—part of the organization's infrastructure—are unavailable.

This triangle can be used to make a number of points. First, the triangle itself can be applied to many levels of the health care system: the practitioner's office, the provider organization (e.g., clinics and hospitals), the health plan, or society. Second, quality improvement interventions can be targeted at each of these levels: the provider organization, health plan, and society. Third, within each level of the health care system, the quality improvement intervention can be targeted at each section of the triangle: organizational culture, infrastructure, and patient-centered care. The three sections in the triangle are interdependent, so an intervention in one section will reverberate through the others.

Fourth, infrastructure and culture are necessary components if true patient-centered care is to be achieved. Fifth, culture is dependent on the leadership in each level of the health care system—the office, the organization, the health plan, and society. Improvement in the health care system is dependent, in part, on whether leaders can be engaged at these different levels.

Finally, a challenge in creating a supportive infrastructure for patient-centered care is the potential for stereotyping. Being able to communicate effectively with a patient does not automatically translate into understanding that specific patient and his or her needs. Infrastructures that standardize the understanding of and response to patients in a particular cultural/linguistic/literacy group (i.e., stereotyping) may lead to the wrong understanding of or response to an individual within that group. Creating an infrastructure without stereotyping individual patients requires understanding the differences within groups as well as between groups.

While recognizing that disparities in processes of care will always exist because each patient and his or her preferences are different, part of health care is managing these differences. Disparities in outcomes can be influenced by appropriate responses to differing patient preferences, as well as unnecessary variability in care processes.

Expectations of how the system should function are necessary to drive change. Expectations about the culture of health care systems include the following:

- *Organizational culture:* Improving care requires awareness, sensitivity, and humility from health care organizations. Recognition that disparities and literacy are relevant to all people is critical because everyone has a language, cultural/ethnic background, and literacy level and is likely to become disabled in some way with aging (e.g., limited vision, hearing, mobility). Organizations should understand the risks that result from ignoring these issues.
- *Education:* Physicians, administrators, and patients and families should be expected to recognize their roles in reducing disparities and improving literacy. All actors should also support each other in understanding and behaving as expected in these roles.
- *Diverse workforce:* The workforce should be diverse to help health care organizations become more innovative in communicating with patients and in making the system better at many levels.

To complement cultural expectations, expectations of the infrastructure must also be addressed, including the following:

- *Supportive infrastructure:* Resource staff, interpretation and translation equipment, and information technology should all be used as necessary enablers of communication, data collection, and analysis.
- *Continuous improvement:* Continuous improvement is a fundamental and ethical responsibility in health care. Providers should pay attention to cultural competency, literacy, and language when working on projects targeting specific diseases or procedures, such as cardiac or diabetes care, not just those projects aimed at culture, literacy, and language.
- *Measurement:* Data are necessary to identify targets for improvement. As mentioned many times, what is not measured cannot be improved. How these variables are measured and how measures are used and stratified should be identified to optimize care delivery.

Evaluation of where we are with respect to these expectations is critical, requiring a sequence of actions to take place. First, there must be an understanding of how evaluation tools should be used, requiring the use of comparative data. Next, there must be external evaluations through accreditation of education and health care. These evaluations require valid measures of care processes and outcomes. The final step of evaluation is third-party public disclosure to validate the reliability of data.

Schyve concluded by discussing the reimbursement system. In health care, all stakeholders should be driven by altruistic incentives to provide higher-quality, safer patient care to meet patients' needs. A secondary incentive for producing better care is reducing the waste of health care resources that result from adverse events and system failures. The reimbursement policy and infrastructure must be transformed to support delivery of better care by reducing disincentives to providing high-quality, safe care and providing incentives to do so.

DISCUSSION

Incentives

Agreeing with the notion that few incentives exist to stratify data, a question arose about the ability of many hospitals to stratify, as the numbers of minority patients may be too low to do so. It was noted that a significant minority of hospitals could in fact stratify even after combining all care into broad groups for specific conditions such as cardiac care. In response, Hasnain-Wynia said that it is important to understand the level at which the intervention is targeted. In this case, the goal is to link data to quality metrics and to make changes through quality improvement. Even when dealing with small patient populations (e.g., a Vietnamese patient population of 20 people), it is important to know what level of care these populations are receiving.

The bigger challenge, Hasnain-Wynia said, is to aggregate and report differences in care in the context of performance incentive programs. It is also important to begin development of methodologies to fill voids in the literature, such as whether certain groups of people or geographic regions can be clustered together.

Communication

In health care, communication with the public is a large problem that needs to be addressed, said Carolyn Clancy of the Agency for Healthcare Research and Quality (AHRQ). Special outreach efforts are needed to communicate with hospital CEOs, especially in the area of health literacy.

Through her research, Hasnain-Wynia noted that the largest communications challenges are with hospital administrators. Although a handful of organizations and leaders understand the issues and are working on them, this understanding and corresponding action are not widespread. In addition, clinicians often do not believe that disparities occur in their own practices or hospitals.

Adverse Effects of Data Collection

Responding to a comment about the patient fear generated in response to data collection, aggregation, and disclosure, Schyve recognized the courage it takes for people to collect and share data that can sometimes uncover unexpected, embarrassing results. Unexpected findings must nevertheless be communicated in order to embolden others to take risks in collecting and using data. Public disclosure of organization-specific data should occur only when appropriate, as premature disclosure may decrease the likelihood that people will collect and use the data for improvement. Data that are used in the aggregate can often demonstrate where a problem exists.

Disparities or Patient-Centered Care?

It is important for individual organizations to understand what data are revealing, Hasnain-Wynia said. For example, in some places it takes longer than recommended standards for black patients with acute myocardial infarction to get from the emergency department to the catheterization lab. Further qualitative analysis of data showed that the reason for this disparity was that many black patients wanted to consult with their primary care physicians before undergoing another service. As another example, Hispanic women often have longer visits because they want to talk with male family members. Are these examples of health disparities or patient-centered care? It is a fine, and sometimes difficult, line to identify. Data tell part of the story, not the whole story, but they help in beginning to reveal what that story is, Hasnain-Wynia said.

Schyve emphasized that it is very common in health care to jump directly from recognizing a problem to choosing a solution, sometimes because that solution was successful in another institution that faced the same problem. This is often inappropriate, though; only data can reveal the specific causes of the problem, which may differ among institutions. Applying the same "solution" to a different cause is likely to waste resources, lead to disappointing results, and leave the problem unresolved.

7

Concluding Remarks

Thomas Boat, M.D.
George Isham, M.D., M.S.
Nicole Lurie, M.D., M.S.P.H.

The chairs of the Forum on the Science of Health Care Quality Improvement and Implementation, the Roundtable on Health Disparities, and the Roundtable on Health Literacy ended the workshop by providing comments on the presentations made during the day.

COLLABORATION AND CREATIVITY

Collaboration, mentioned frequently throughout the workshop, is needed to facilitate change, said Boat, Isham, and Lurie. More frequent collaboration across the silos of disparities reduction, health literacy, and quality improvement is needed.

Collaboration was also discussed in terms of working with communities. Sharing responsibility with communities requires that the context in which care is delivered be clearly characterized, Isham said. Characterizing populations to generate common agendas between care delivery organizations and local public health agencies builds a bridge between these two important players as they work to improve the health of individuals and the population. Practice tools are needed to drive meaningful collaboration from these two fragmented systems.

Lastly, collaboration between health care systems and other industries can influence quality, Lurie said. Many problems with the delivery of health care could more effectively be solved by collaborating with others. Ways in which others have worked through communication problems are abundant, such as using pictures but not words to clearly communicate instructions for operating construction tools and airplane exit doors. Drawing from Wolf's and Pignone's discussions (see Chapters 3 and 4), innovative methods for communication have been developed by others and should be creatively used in health care.

Education is an important field for collaboration, Lurie said. The bridge connecting health literacy and basic education needs more attention, as increased graduation and GED rates are fundamental for health and health literacy. Leaders in both communities must engage in cross-cutting conversations. Those in the health field must pay attention to how general education, performance measures, and accountability influence patients' health care. Bridges must be built with other fields that have components that overlap with health. Learnings from these bridges should be leveraged and shared, Isham said.

COMMUNICATION

Communication is at the heart of quality care and needs to be improved, Boat said. A growing body of literature describes effective ways to communicate. For example, motivational interviewing, which uses open-ended questions and reflective interchanges of words, is being adopted in various health care settings. Physicians lack knowledge about how to communicate effectively, including how to listen to patients and provide them with opportunities to share information necessary for developing the best possible action plan, Boat said. Changes in health professions training are needed to improve clinician communication.

DATA, MEASURES, AND STANDARDIZATION

As discussed throughout the workshop, data are necessary but not sufficient to drive action, requiring the development of new methods and incentives, Lurie said. While the moral imperative is enough for some providers, others require financial incentives, resulting in the development of pay-for-performance programs. Such programs must be implemented carefully, however, as they may disadvantage some populations. Other types of individual incentives, such as cash transfers, should also be explored, Lurie said. Such programs are being tested in Mexico and New York City to get people into care. Institutional incentives should also be put in place to obtain more resources for those serving disadvantaged populations.

The push to standardize care but also to customize care presents a dichotomy, Isham said. Arriving at the right balance between standardization and customization for every patient, every time, is an incredibly difficult challenge, especially in the largely fragmented health care industry. This balance must be kept at the forefront of efforts to develop more standards and to provide individually tailored care.

DEVELOPING LITERACY THROUGHOUT THE LIFE SPAN

Literacy, in general, is achieved in the first 10 years of life, but the implications for health literacy are unclear, Boat said. It may be necessary to lay the foundation for people's understanding of health in the first years of life, such as teaching the importance of diet, exercise, and sleep. We need to think creatively about universal approaches to literacy, potentially involving preschools, schools, and primary care. Lurie agreed, stating that the health care system should also be designed to teach health literacy over the course of a patient's life, beginning with early development and adapting through old age.

AT-RISK POPULATIONS

Different populations require different delivery models to provide the best care; for example, at-risk populations and immigrants may require special attention. The successful execution of each model is critical to developing appropriate interventions, Boat said. The capacity for health literacy in these populations, as well as their ability to participate in programs to improve their own care, must be assessed. Community interventions may be an important strategy to assess health literacy, especially for children. One-third of children in underserved areas receive home visitations, which provide assessment and care of mixed quality; this is an opportunity to assess what parents know, identify what children are being exposed to, and develop appropriate interventions.

Another group that may require special attention is immigrants, Lurie said. Immigrant populations encounter the health care system as families, because children often accompany family members to help translate and navigate the system. The system must change to accommodate the looming demographic transitions facing the country and avoid the perfect storm, described in Chapter 2.

MODELS OF CARE

The medical home is not yet well defined and means different things to different people, Isham said. One version of the medical home focuses on cultural and health literacy problems and faces the challenge of evaluating patient complexity at the point of care while also tailoring care to the patient. The use of payment models to catalyze development of this model should be explored.

Revisiting Somers's point, Isham noted that infrastructure that facilitates integration of disparities reduction and health literacy improvement must be built for physicians in solo practices, given the many individuals who receive such care. Furthermore, clinician training, among other infrastructure needs of these delivery models, is needed.

SELF-MANAGEMENT

Health literacy is the process of obtaining, processing, and understanding information important to health—information on which people must be empowered to act, Boat said. Self-management is an important concept of care organization. To facilitate self-care, patients should be educated to participate in care processes. Furthermore, it is the responsibility of clinicians to assess their patients' level of confidence and to encourage patients to become involved in developing action plans for their own care. Additionally, mechanisms are needed to evaluate the ongoing success of these efforts.

CONCLUSION

Each chair suggested that continued collaboration among those in health literacy, disparities reduction, and quality improvement could lead to new and exciting opportunities to positively affect health care and improve health outcomes. Specific steps for progress include

- using data to drive action;
- teaching health literacy over the life course;
- focusing interventions on target populations;
- finding a balance between standardization and customization of health care; and
- enhancing organizational capability to address disparities, literacy, and quality.

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Appendix A

Workshop Agenda

Toward Health Equity and Patient-Centeredness: Integrating
Health Literacy, Disparities Reduction, and Quality Improvement

Fairmont Newport Beach
Newport Beach, CA
8:00 am–5:00 pm

Outcomes of workshop

1. Review the current evidence base for quality improvement approaches that address health literacy and/or reduce disparities
2. Describe several paradigmatic efforts to use quality improvement to address health literacy and/or reduce disparities
3. Explore several key conceptual and policy questions for quality improvement strategies to address health literacy and/or reduce disparities
4. Make linkages between quality improvement, health literacy, and disparities reduction, with improving equity and patient-centeredness as the focus

May 12, 2008, Public Workshop

8:00–8:15 Opening Remarks
Speaker: Ignatius Bau, The California Endowment

8:15–8:45 Vision for better health outcomes: Integration of disparities reduction, health literacy, and quality improvement
Speaker: George Isham, HealthPartners

8:45–9:30 Building the foundation for integrating health literacy, disparities reduction, and quality improvement in health and health care
Moderator: Ignatius Bau, The California Endowment

- Health Literacy: A Matter of Health Care Quality and Equity
  Speaker: Michael Wolf, Northwestern University

- Integrating Health Literacy, Disparities Reduction, and Quality Improvement
  Speaker: Cindy Brach, Agency for Healthcare Research and Quality

- Patient-Centeredness as an Indicator of Quality—Measures of Patient-Centeredness and How Issues of Health Literacy and Health Disparities Interact to Impact Quality
  Speaker: Mary Catherine Beach, Johns Hopkins University

9:30–10:00 Discussion

10:00–10:15 **Break**

10:15–11:00 Integration at the practitioner level: Using quality improvement as a tool to improve health literacy and reduce disparities

Speakers will describe the type of system in which they work, and why they see integration as important for that system, and discuss how approaches to improve quality and health literacy and reduce disparities might be used in that system to improve equity and patient-centered care.
Moderator: Jack Lewin, American College of Cardiology
Speakers:

- Health plan—Grace Ting, WellPoint
- Ambulatory care—Tom Sequist, Harvard Vanguard
- Hospital—Michael Pignone, University of North Carolina

11:00–12:00 Responses and reflections on using quality improvement
Speakers: Nicole Lurie, RAND; Marshall Chin, University of Chicago; Steve Somers, Center for Health Care Strategies, Inc.

12:00–1:30 **Lunch**

1:30–2:30 Breakout Session

- Health plans
  Leader: Alicia Dixon, The California Endowment
- Ambulatory care
  Leader: Carolyn Clancy, Agency for Healthcare Research and Quality
- Hospital
  Leader: Thomas Boat, Cincinnati Children's Hospital Medical Center

Questions to be discussed:

1. Describe a specific activity that effectively integrates quality improvement, disparities reduction, and addressing health literacy.
2. How can such integration be more patient-centered?
3. What systems integration and systems changes might be necessary to achieve greater patient-centeredness and equity?

2:30–3:15 Group Reports
Moderator: Marshall Chin, University of Chicago

3:15–3:30 **Break**

3:30–4:00 Policy Issues of Integration
Issues to be addressed include

- What standards/priorities should be put in place to foster improvement in patient-centered care and equity?
- What types of measures need to be developed?
- How can efforts be evaluated?
- Financing
- Education and training

Moderator: Winston Wong, Kaiser Permanente
Speakers:
- National: Paul Schyve, Joint Commission
- Other: Romana Hasnain-Wynia, Northwestern University

4:00–4:15 Discussion
Moderator: Winston Wong

4:15–5:00 Summary/conclusions: Closing remarks from chairs of forums/roundtables

5:00 **Adjourn**

Appendix B

Workshop Participants

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Amgen

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Community Health
Organizations

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Cathy Coleman
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