



Easing the Burden

Using Health Care Reform to Address Racial and Ethnic Disparities in Health Care for the Chronically Ill

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Introduction and summary

Chronically ill Americans from racial and ethnic minorities have much to gain from the implementation of the Affordable Care Act. These Americans are more likely to be without health insurance coverage—they make up more than half of America’s uninsured—and they suffer higher rates of chronic illness than the general population. They are more likely to have the risk factors such as obesity that predispose them to chronic illnesses, and are less likely to receive the preventive screenings, regular care, and necessary medications that could prevent or ameliorate their chronic conditions.

Being uninsured often means postponing needed health care services. That’s why people of color in our nation are diagnosed at more advanced disease stages, and once diagnosed, they receive poorer care. Nearly half (46 percent) of nonelderly black adults and more than a third (35 percent) of nonelderly Hispanic adults who do not have insurance report having one or more chronic health conditions. Many more of these Americans do not have a usual source for health care, have substantially higher unmet health needs than their insured counterparts, and have high out-of-pocket costs.¹

Inevitably, they are sicker and die sooner.²

This paper will focus primarily on how implementation of provisions in the new health care reform law can help those who benefit the least from our current health system by addressing disparities in prevention, diagnosis, and treatment of chronic illnesses, thus easing the additional health care burdens borne by racial and ethnic minorities with chronic conditions.

A key tenet of health care reform and making the health care system sustainable into the future is the recognition that most chronic diseases can be prevented. Improving access to prevention services, in combination with better management and coordination of the care delivered to the chronically ill, is an investment that pays off in the medium term with reduced rates of health care services utilization, and in the long term with better health outcomes and more productive lives at lower cost.

This paper addresses five key issues in addressing current racial and ethnic disparities in the prevention, diagnosis, and treatment of chronic illnesses:

- Improving access to health insurance coverage
- Improving access to primary care
- Addressing disparities in treatment and quality of care
- Providing culturally competent care
- Improving patient literacy

Each of these issues is discussed in the pages that follow, looking first at the current situation, then at how this can be addressed through the implementation of select provisions of the Affordable Care Act, and finally at the difference these reforms can potentially make in the lives of minority Americans with chronic illnesses or at risk of chronic illness.

The ultimate goal must be that all Americans, regardless of race or ethnicity, get the quality health care services they need when they need them. We can ill afford to ignore the high cost in dollars and human life that the nation pays each year that is attributed to health care disparities, especially when much of the burden from chronic illnesses is preventable. The total annual cost of racial and ethnic health disparities, including direct medical costs and indirect costs such as lost productivity, lost wages, absenteeism, family leave, and premature death, is of the order of \$415 billion.

The causes of health disparities are complex, but we know that the time to take action is now.

The current situation

The factors that give rise to increased rates of chronic illness in racial and ethnic minorities

Racial and ethnic minorities in our nation experience disparities across a significant number of health status measures and health outcomes. Issues such as income, education, and work status as well as poor housing, neighborhood segregation, and other environmental factors within communities drive these racial and ethnic differences. But disparities in health status and outcomes may also result from failures within the health care system. Problems accessing services and a lower quality of care for racial and ethnic minorities clearly impact the health of these populations.

Minorities generally rate their health as poorer than whites. Almost half of black adults report having a chronic illness or disability. The disparities in chronic illness between blacks and whites persists across income levels and after adjusting for age. Disparities are also widespread across a number of risk factors for disease and disability, including obesity and smoking.³

Adult obesity rates for African Americans and Hispanics are higher than those for whites in nearly every state of the nation. Adult obesity rates for African Americans are greater than or equal to 30 percent in 43 states and the District of Columbia. In nine states, the rates exceed 40 percent. Adult obesity rates for Hispanics are greater than or equal to 30 percent in 19 states.⁴ Higher rates of obesity translate into higher rates of obesity-related diseases, such as type 2 diabetes and heart disease, so it is no surprise that African Americans and Hispanics have higher rates of diabetes, hypertension, and heart disease than other groups.⁵

Diabetes is a major risk factor for heart and kidney diseases and other conditions causing severe disability. American Indians/Alaska Natives are at the greatest risk for diabetes; nearly 18 percent of this population suffers from diabetes. Nearly 15

percent of African Americans and 14 percent of Hispanics have been diagnosed with diabetes compared with 8 percent of whites.⁶ Many people with diabetes remain undiagnosed, and those who have reduced access to health care are more likely to have their diabetes unrecognized and untreated.⁷ If current trends continue, one in every two minority children born today will develop type 2 diabetes at some point in their lives.⁸

Black women have a higher prevalence than white women for four related conditions—heart failure, coronary heart disease, hypertension, and stroke. Black men have a higher prevalence than white men for three of the four conditions—heart failure, hypertension, and stroke.⁹

African Americans experience higher incidence and mortality rates from many cancers that are amenable to early diagnosis and treatment. For instance, they are more likely than whites to suffer from colorectal, prostate, and cervical cancers, and they are also more likely to die from these cancers. Hispanics have a higher incidence rate of infection-related cancers, including stomach, liver, and cervical cancers. Hispanic women are less likely to be screened for cervical cancer than both white and black women.¹⁰

Although white women have the highest incidence of breast cancer, black women have the highest mortality rate from this cancer among all races and ethnicities. While black women are just as likely as white women to get a mammogram, they are less likely to get timely access to quality care if they then receive an abnormal diagnosis.¹¹

Asthma is another health condition that disproportionately impacts minorities. Asthma prevalence is highest among blacks, followed closely by American Indians/Alaska Natives. More than 9 percent of these minority groups suffer from asthma, compared to 7.6 percent of white Americans. Deaths from asthma, an outcome that should be wholly preventable through effective management of the disease, are also higher among this group.¹²

Disparities exist in both access to and quality of mental health care for racial and ethnic minority groups. Examples of these disparities include the underutilization of psychiatric services by persons from ethnic minority groups, problems in getting people from these groups to seek treatment, and the inappropriate prescribing of antipsychotic medications for African Americans and Hispanics. American Indians/

Alaska Natives have the highest rates of frequent mental distress, with nearly 18 percent of the population reporting 14 or more mentally unhealthy days, and this group also has high rates of substance use disorders and completed suicide.¹³

The costs of racial and ethnic disparities in health care for the chronically ill

The reduction or elimination of racial and ethnic disparities in health care can be viewed as a moral imperative or a goal for a health care system that is based on quality, but it is also an economic issue. Minority Americans bear excess rates of chronic disease that impose cost burdens on public programs as well as individuals and other purchasers of private health insurance.

A recent paper from the Urban Institute estimated that in 2009, disparities among African Americans, Hispanics, and non-Hispanic whites as a consequence of elevated rates of selected chronic illnesses (diabetes, hypertension, stroke, and renal disease) and general poor health cost the health care system \$23.9 billion.¹⁴ Most of this expenditure (\$15.6 billion) was for Medicare, although private insurers spent \$5.1 billion. Out-of-pocket costs were more than \$2 billion. Even without taking into account projected growth in per capita health care spending, these annual costs will more than double to \$50 billion by 2050 as the number of elderly Hispanics and African Americans increases.

The estimated total cost of these disparities is approximately \$337 billion, including \$220 billion for Medicare over the 10-year period from 2009 through 2018. In reality these costs are much larger, as this analysis considered only selected chronic diseases among two minority groups, and they did not include nursing home costs.

The Joint Center for Political and Economic Studies commissioned a study that provides some insight into the full extent of the financial burden that racial and ethnic disparities are putting on the health care system and society at large.¹⁵ The study found that between 2003 and 2006, 30.6 percent of direct medical care expenditures for African Americans, Asians, and Hispanics were excess costs due to health disparities. When the indirect costs of these disparities such as lost productivity, lost wages, absenteeism, family leave, and premature death were included, the total cost was \$1.24 trillion. Eliminating health disparities for minorities would have reduced direct medical care expenditures by \$229.4 billion over the three years studied.

Offset against these costs to the health care system are the costs of the interventions to address health care disparities, so it is essential to consider the “business case” for these.¹⁶

These new costs may come from adding health care personnel, better educating patients or providers, and providing additional services. Any new cost can pose a substantial barrier to a health care provider’s willingness to introduce and sustain new interventions. This practical reality holds true even though the intervention may be expected to add value by reducing disparities in the care provided, by raising the quality of services for minority patients, by reducing the downstream need for services, or by improving the future health of disadvantaged patients.

Easing the burden

Tackling chronic illness among American racial and ethnic minorities

Many factors give rise to increased rates of chronic illness in racial and ethnic minorities, and not all of them have their origins in the health care system. Pronounced disparities in health status mirror inequities in a range of social and economic factors (such as income, education, employment status and working conditions, social networks and community cohesion) and environmental factors (such as clean air and water, the built environment, and the availability of safe and affordable housing, transportation, and nutritious foods).

The critical role of these factors in determining health status, however, does not diminish the importance of an equitable approach to delivering quality, affordable, and timely health care services and addressing behavioral risks such as smoking and physical inactivity.

This paper addresses the following as the key issues in addressing current racial and ethnic disparities in the prevention, diagnosis, and treatment of chronic illnesses:

- Improved access to health insurance coverage
- Improved access to primary care
- Addressing disparities in treatment and quality of care
- Provision of culturally competent care
- Improved patient literacy

Let's examine each of these items in turn.

Improved access to health insurance coverage

The current situation

The Institute of Medicine found that insurance status, more than any other demographic or economic factor, determines the timeliness and quality of health care, if it is received at all.¹⁷ Among the nonelderly, 36 percent of Hispanics, 33 percent of American Indians/Alaska Natives, 22 percent of African Americans, 17 percent of Asian and Pacific Islanders, and 13 percent of whites are uninsured.¹⁸

The extent of medical care and the location where that care is delivered varies with insurance status. Lack of insurance is associated with less care in all settings except the emergency department.¹⁹ Compared to people who have health insurance, the uninsured receive less preventive care, are less likely to have an early diagnosis of their disease, and once diagnosed, receive less care and have higher mortality rates.

Regardless of income, people with a chronic illness have often found it difficult, if not impossible, to get affordable health insurance coverage. (see Table 1)

TABLE 1
Chronically ill and uninsured

Percentage of nonelderly adults with chronic conditions who lack health insurance coverage

Adults with	Percentage uninsured
Any chronic condition	17%
White	13%
African American	19%
Hispanic	35%
Hypertension	14%
Heart disease	13%
Asthma	18%
Diabetes	15%
Arthritis	12%

Source: Amy J. Davidoff and Genevieve M. Kelley, "Uninsured Americans with Chronic Health Conditions: Key Findings from the National Health Interview Survey" (Princeton, NJ: Robert Wood Johnson Foundation, 2005).

How this will change under health care reform

When the provisions of ACA are fully implemented by 2014, some 32 million Americans who currently do not have health insurance coverage will be covered, and coverage will be more affordable for many millions more.

- People with an income below 133 percent of the poverty level (currently \$14,404 for a single person and \$19,378 for a couple), including those without dependent children, will be eligible for Medicaid.
- People making up to four times the poverty threshold will get subsidies on a sliding scale to help them purchase insurance coverage through the new health insurance exchanges.
- The health insurance exchanges that will enable the uninsured to access affordable, quality health care will provide a new transparent and competitive insurance marketplace where individuals and small businesses can buy health benefit plans. Exchanges will offer a choice of health plans that meet required benefits and cost standards.
- Eligible small businesses will receive subsidies to help them purchase health insurance coverage for their employees.
- Large businesses that fail to help employees get health insurance coverage will be financially penalized.

A number of measures to reform health insurance will particularly benefit people with chronic illnesses or at risk for developing a chronic illness.

- A Pre-Existing Condition Insurance Plan will provide new coverage options to individuals who have been uninsured for at least six months because of a pre-existing condition. These plans are currently being established in each state and will operate until 2014, when all discrimination against pre-existing conditions will be prohibited.
- Annual out-of-pocket medical costs will be capped at \$5,950 for individuals and \$11,900 for families (indexed).
- Insurers cannot deny coverage or charge higher premiums because of a person's sex or health status.

- All new plans must offer a minimum package of benefits defined by the federal government, including certain preventive services without any costs.

Why this is important for racial and ethnic minorities with chronic illnesses

Many studies demonstrate that uninsured American adults receive less appropriate care and fewer needed health services than their insured peers.²⁰

A 2001 study looked at the effects of being uninsured on ethnic minorities' management of chronic illness and found that, compared with insured respondents, uninsured respondents were much less effective at managing their illnesses.²¹ The uninsured had poorly controlled illnesses, frequent health crises, difficulty procuring medication, used medication incorrectly, demonstrated poor understanding of their illness, and displayed little knowledge of self-care measures or risk awareness. They rarely had a regular physician or attended a specific health clinic. Lack of money was the primary reason given for not seeking health care and respondents often reported feeling extremely ill before they sought care. Those who had identified and used a free clinic were much less likely to delay seeking care.

Uninsured near-elderly people (those aged 55–64) represent a particularly vulnerable population. The risks of experiencing major health problems and incurring substantial medical expenses increase dramatically for this age group, so the consequences of lacking insurance are more severe.²²

Expanding coverage to the near-elderly uninsured may greatly improve health outcomes for these groups and may also lead to reduced Medicare spending for those previously uninsured.²³ For example, a comparison of health care use and spending after age 65 for a group of Americans who did not have health insurance before qualifying for Medicare with that of a group of Americans who were continually insured found that the previously uninsured spent a mean of \$1,023 more in their first year in Medicare. The spending difference was larger for people with diabetes, heart disease, and arthritis.²⁴

Insurance coverage alone, however, may not reduce mortality for near-elderly African Americans. One study suggests that insurance may be insufficient to overcome lifelong risk factors for ill health and mortality, including income inequality and broader discrimination and biases.²⁵

Improved access to primary care

The current situation

Primary care is the underpinning of the health care system and research studies have shown that having a usual source of care raises the chance that people receive adequate preventive care, early diagnosis, and other important health services.

Data show that:

- About 30 percent of Hispanic and 20 percent of African Americans lack a usual source of health care compared with less than 16 percent of whites.
- African Americans and Hispanics are far more likely to rely on hospitals or clinics for their usual source of care than are white Americans.²⁶

Chronically ill, uninsured patients are four to six times more likely than sick patients with insurance to have problems accessing care.²⁷ (see Table 2) A 2008 survey by the Commonwealth Fund found that compared to patients in seven other countries, chronically ill adults in the United States are far more likely to

TABLE 2
Chronically ill and lacking care

Percent of adults with chronic illness who lack a usual source of health care, by insurance status

Adults with	Percent without a usual source of care		
	All adults	Uninsured	Insured
Any chronic condition	11%	38%	5%
White	9%	36%	5%
African American	11%	33%	5%
Hispanic	20%	46%	6%
Hypertension	7%	30%	3%
Heart disease	8%	37%	4%
Asthma	10%	36%	5%
Diabetes	5%	25%	2%
Arthritis-related conditions	7%	30%	4%

Source: Amy J. Davidoff and Genevieve M. Kelley, "Uninsured Americans with Chronic Health Conditions: Key Findings from the National Health Interview Survey" (Princeton, NJ: Robert Wood Johnson Foundation, 2005).

skip care because of costs.²⁸ More than half (54 percent) of American chronically ill patients did not get recommended care, fill prescriptions, or see a doctor when sick because of costs, compared to 7 percent to 36 percent in other countries.

People with chronic illnesses who don't receive regular medical care run the risk of disabling and expensive consequences. For instance, individuals whose diabetes is not properly controlled are more susceptible to blindness, nerve damage, limb amputation, or dialysis for the rest of their lives.

How this will change under health care reform

The emphasis in ACA on improving primary care will particularly benefit people from racial and ethnic minorities with chronic illnesses.

- Primary care capacity will be boosted through a range of investments and payment incentives, including a 10 percent Medicare bonus payment for primary care and general surgeons; an additional 10 percent Medicare bonus for primary care physicians practicing in health professional shortage areas; and graduate medical education reforms that redistribute residency positions, promote training in outpatient settings, and support the development of primary care training programs.
- The new Center for Medicare and Medicaid Innovation will develop and expand the medical home model for Medicare and Medicaid patients. Medical homes—health care settings that provide patients with timely, well-organized care and enhanced access to providers—are associated with a reduction in health care disparities for adults and better access to preventive services.
- The states are provided with an option of enrolling Medicaid beneficiaries with chronic conditions into a health home. Health homes would be composed of a team of health professionals and would provide a comprehensive set of medical services, including care coordination.
- A program is created to establish and fund community health teams to support medical homes by providing increased access to comprehensive, community-based, coordinated care. Community health teams usually include care coordinators, nutritionists, behavioral and mental health specialists, nurses and nurse practitioners, and social, public health, and community health workers. Team members work together with providers, patients, and their families to prevent

chronic illnesses such as diabetes, hypertension, and heart disease and coordinate and manage patient care.

- New funding will establish more community health centers to provide comprehensive, affordable care that is responsive and customized to the low-income, racial, and ethnic minority communities they serve.

Why this is important for racial and ethnic minorities with chronic illnesses

Recent research indicates that access to a “medical home” is a strong indicator of quality of care. When adults have a medical home that provides timely, well-organized care and enhanced access to the needed range of health providers, racial and ethnic disparities in access and quality are reduced or eliminated. With a medical home, minority patients are just as likely as nonminority patients to have care when needed, receive preventive screening, and have chronic conditions managed appropriately.²⁹

Indeed, data show that when patients with diabetes from low-income minority groups are provided with affordable access to primary care and pharmacy services, hospitalization rates are reduced.³⁰

The expansion of community health centers is also an effective way to deliver care, especially to communities that are otherwise medically underserved. They deliver improved health outcomes for their patients, diminish health gaps for racial and ethnic minorities, and lower the cost of treating chronically ill patients.³¹

Community health centers are required to provide comprehensive health and enabling services, to tailor these to fit the special needs and priorities of their communities, and to provide linguistically and culturally appropriate services. They are open to all residents, regardless of income, with sliding scale fee charges for out-of-pocket payments based on income and ability to pay.³²

Health centers improve access to timely screening and preventive services for minority patients who would not otherwise have access to certain services and eliminate disparities by race/ethnicity or insurance status in receiving preventive services. Hispanic and African-American women who attend community health centers are more likely to receive mammograms and pap smears compared to their counterparts nationally.³³

Health centers meet or exceed nationally accepted practice standards for the management and treatment of chronic conditions. The Institute of Medicine and the Government Accountability Office both recognize health centers as models for screening, diagnosing, and managing chronic conditions such as diabetes, cardiovascular disease, asthma, depression, cancer, and HIV.³⁴ Ninety percent of Hispanic and African-American health center patients with hypertension, for example, report that their blood pressure is under control. This is more than triple that of comparable national groups.³⁵

Community health teams can help with targeting the right patients, medication, testing adherence, transitional care programs after patients are discharged from the hospital, and the coordination of care across a range of providers.

Addressing disparities in treatment and quality of care

The current situation

There are significant disparities in the quantity and quality of care delivered to racial and ethnic minorities across all areas. A number of studies have found that even after controlling for patient age, severity of illness, health insurance, and hospital type, African Americans and Hispanics are significantly less likely than whites to receive needed therapeutic procedures.³⁶ Racial and ethnic minorities receive a lower quality and intensity of care than other Americans who present identical health problems.³⁷

About 84,000 deaths occur in the United States each year due to the health care gap that separates minorities from nonminorities.³⁸ This is unacceptable ethically and generates huge social and economic costs on the individuals and communities involved and on the public at large.

Receiving medical treatment in a timely fashion is important for reducing mortality and long-term disability from many conditions, including stroke, heart attack, and bacterial infections. Minority patients often experience longer wait times for health care, both in the outpatient and acute care settings.³⁹

Racial and ethnic minorities are also at risk for problematic access to pain care and poor pain assessment. They often receive inferior treatment for their pain complaints for all types of pain and across all kinds of treatment settings.⁴⁰

Minority groups are grossly underrepresented in clinical trials. According to statistics compiled by the Intercultural Cancer Council, 88.8 percent of those enrolled in clinical trials between January 2003 and June 2005 were whites, compared to 8 percent who were African Americans, 2.8 percent who were Asians/Pacific Islanders, 0.5 percent who were Native Americans/Alaska Natives, and 0.1 percent who were other races.⁴¹ Only 5.6 percent of all patients were Hispanics compared to 94.4 percent who were non-Hispanics.

The consequence of this underrepresentation is twofold. Patients with serious illnesses are denied access to potentially life-saving treatments. And many treatments that are tested have insufficient data about their safety and efficacy in minority groups. This latter point can be crucial when genetic disparities affect the efficacy of a new medicine.

Each year in the United States medical errors cause an estimated 44,000 to 98,000 deaths and cost an estimated \$29 billion in lost income, disability, and increased health care costs.⁴² Errors and avoidable complications from surgery affect people of color more than whites. Asians and Hispanics, for example, are more likely to die from complications during hospitalization than whites, and African Americans are much more likely to suffer postoperative pulmonary embolism or deep vein thrombosis than whites.⁴³

The sources of these disparities are the subject of considerable debate. Emerging evidence points to variation in quality among providers depending on the race or ethnicity of their patients. This may be due to the inability of primary care doctors, especially those who care for racial and ethnic minorities, to provide timely and affordable access to high-quality subspecialists, diagnostic imaging, ancillary services, and nonemergency hospital admissions.⁴⁴

How this will change under health care reform

There are a number of provisions in ACA that will address disparities in treatment, health care quality, and safety. Identifying priorities in health care quality and the developing quality measures and performance indicators will help improve health care services and patient outcomes for all Americans, but improvements will disproportionately benefit those segments of the population which are least likely to get quality care. Initiatives include:

- The establishment of a National Strategy to Improve Health Care Quality to improve the delivery of health care services, patient health outcomes, and population health. Funding is provided for the development of quality measures at the Agency for Healthcare Research and Quality and the Centers for Medicare and Medicaid Services, for the collection of performance information, and for public reporting on this. An Interagency Working Group on Health Care Quality comprised of federal agencies will collaborate on the development and dissemination of quality initiatives consistent with the national strategy.
- A requirement for the secretary of health and human services to develop guidelines for use by health insurers to report information on initiatives and programs that improve health outcomes through the use of care coordination and chronic disease management, prevent hospital readmissions and improve patient safety, and promote wellness and health.
- A requirement for the secretary of HHS to identify and publish a core set of quality measures for Medicaid-eligible adults (as for Medicaid-eligible children), and for the secretary and the states to report against these measures will benefit many people of color.
- Linking payment to quality outcomes under the Medicare program. This includes:
 1. A value-based purchasing program for hospitals, under which a percentage of hospital payment will be tied to performance on quality measures related to common and high-cost conditions, such as cardiac, surgical, and pneumonia care .
 2. Improvements to the physician quality reporting initiative program, which provides incentives to doctors who report quality data to Medicare .
 3. Payment adjustments for health care-acquired conditions such as infections.

In addition, the ability to drive efforts to address disparities will be boosted by requirements for more data and by raising the profile of minority health and research into understanding and addressing health care disparities. Two specific initiatives which will do this are:

- Codifying the Office of Minority Health at the Department of Health and Human Services and a network of minority health offices located within HHS. The Offices of Minority Health will monitor health, health care trends, and quality of care among minority patients and evaluate the success of minority health programs and initiatives.

- Elevation of the National Center on Minority Health and Health Disparities at the National Institutes of Health from a center to an institute.

Why this is important for racial and ethnic minorities with chronic illnesses

While the causes of disparities in treatment and quality of care are many, a consistent focus on quality is one very effective way to help render the health care system “blind” to the race and ethnicity of the patient and ensure that every patient gets the best, most appropriate treatment and care in a timely fashion.

This is particularly true for those patients with chronic illnesses. Often these patients have multiple illnesses and the secondary effects of disease processes such as stroke and kidney failure, which may limit mobility. Their ability to coordinate their care across a range of providers and manage their medication regimes may be limited.

That’s why new ways of funding and delivering coordinated care services, through initiatives such as the establishment of medical homes and accountable care organizations—which are also required to focus on quality and patient outcomes—will be important for this population group.

Other initiatives in health care reform that will make a difference here are the provisions that will help ensure culturally competent care, and the multitude of requirements for the collection and analysis of data around racial and ethnic disparities in particular and the quality of care and health outcomes in particular. It will be critical that the data collected and the research conducted by the Institute on Minority Health and Health Disparities is directed at better understanding and addressing the significant disparities in the quantity and quality of care delivered to racial and ethnic minorities.

Provision of culturally competent care

The current situation

Clear communication is essential to healthy patient outcomes even when there is no language barrier. At least 66 million patient-provider encounters occur across language barriers each year.⁴⁵ Without interpreter services, these patients have a more difficult time obtaining medical services, receive lower-quality health care,

and have a greater chance of experiencing negative health outcomes. As many as one in five Spanish-speaking Americans report not seeking medical care because of language barriers.⁴⁶

Research suggests that health care providers' diagnostic and treatment decisions, as well as their feelings about patients, are influenced by patients' race or ethnicity.⁴⁷ Additionally, patient-provider communication has been linked to health outcomes and patient satisfaction.⁴⁸

Several studies show that racial and ethnic concordance between health care professional and patient is substantially and positively related to patient satisfaction, although it is not essential for patient satisfaction.⁴⁹ Quite simply, patients feel most comfortable with doctors similar to themselves. Because blacks, Hispanics, and American Indians/Alaska Natives in particular are very underrepresented in the health care professions, this means that it is significantly more difficult for most racial and ethnic minorities to find a health care provider that they trust to provide regular care.

In 2004, the Sullivan Commission on Diversity in the Healthcare Workforce examined disparities and diversity in the health care system and noted that “the lack of minority health professionals is compounding the nation’s persistent racial and ethnic health disparities.”⁵⁰ Indeed, minority representation in the health professions grew at a snail’s pace over the past several decades. The proportion of U.S. physicians who are minorities is just 6 percent, the same proportion as a century ago.⁵¹ African Americans represent 5 percent of registered nurses and 12 percent of the population. Hispanics represent about 4 percent of registered nurses and 15 percent of the population. Asian Americans fall short, too, with 3 percent of registered nurses and nearly 6 percent of the population.⁵²

A 2007 report that looked at cultural and linguistic services in hospitals found that much needs to be done to address cultural and linguistic barriers, particularly in the areas of language access services, informed consent and related patient education processes, and the collection and use of patient demographic data.⁵³ Although many different types of training courses have been developed to help health care professionals provide services in a culturally competent manner, these efforts have not been standardized or incorporated into training for health professionals in any consistent way.

How this will change under health care reform

ACA has provisions to ensure an increase in the cultural diversity of the health care workforce. These include:

- Initiatives to increase the diversity of the workforce by the provision of scholarships and financial assistance to disadvantaged students who commit to work in medically underserved areas and serve as faculty in eligible institutions.
- Grants to states, public health departments, clinics, and hospitals to promote the use of community health workers in medically underserved areas. This type of peer outreach and education model has been shown to be effective in creating a bridge between providers of health, social, and community services and the underserved and hard-to-reach populations they serve. Community health workers offer interpretation and translation services, provide culturally appropriate health education and information, offer informal counseling and guidance on health behaviors, advocate for individual and community health needs, and can provide some direct primary care services and screenings.
- Programs to support the development, evaluation, and dissemination of model curricula for cultural competency for use in health professions schools and continuing education programs are reauthorized and expanded.

Why this is important for racial and ethnic minorities with chronic illnesses

Increasing the number of underrepresented groups in the health professions can help address health care disparities by both improving access and responding more effectively to the needs of minority populations. Studies show that minority health care professionals are more likely to work in underserved areas.⁵⁴

Greater health professions diversity will also provide increased opportunities for minority patients to see practitioners with whom they share a common race, ethnicity, or language. Race, ethnicity, and language concordance is associated with better patient-practitioner relationships and communication, and increases patients' likelihood of receiving and accepting appropriate medical care.⁵⁵

Culturally sensitive care can help providers understand what complementary and alternative treatments patients might be using, to recognize mental health problems that might otherwise be hidden, and to address concerns about sensitive issues such as sexuality and end-of-life care that are not easily discussed.

The provision of culturally and linguistically appropriate informational materials and translational services are also essential to ensuring that racial and ethnic minorities can navigate the health care system effectively and access all the benefits to which they are entitled.

Improved patient literacy

The current situation

Health literacy—the ability to read and comprehend basic health information—is an important barrier to the effective management of chronic illness. It is associated with a higher use of health services and may well directly contribute to poorer patient outcomes.⁵⁶ Patients who have marginal or inadequate functional health literacy will have difficulty reading, understanding, and interpreting most written health texts and instructions and they are more likely to misunderstand directions for health care.

Consequently, these patients are also more likely to take medications incorrectly and more likely to fail to follow a prescribed diet or treatment regimen. Health care experts postulate that the higher rates of poor health literacy in racial and ethnic minorities may represent an important variable contributing to higher rates of diabetes complications in minority groups.⁵⁷

Other factors apart from reading and comprehension may also come into play. Case in point: A research study on knowledge and care of chronic illness in ethnic minority groups found that Hispanics did not hold mainstream cultural views of health and the management of illness. Their knowledge about illnesses was quite variable, and although they described symptoms clearly, they were, almost without exception, vague about the details of illness management. This meant that the group studied did not understand that they had a role in managing their illness beyond taking medication.⁵⁸

The use of alternative therapies instead of or alongside mainstream therapies is common among Hispanics, and many use therapies that may be unfamiliar to health care practitioners.⁵⁹

How this will change under health care reform

The major efforts to address health literacy across the board—for providers, patients, the media, and government agencies—will come as a result of the National Action Plan to Improve Health Literacy that was released by the Department of Health and Human Services in May 2010. The plan calls for improving the jargon-filled language, dense writing, and complex explanations that often fill patient handouts, medical forms, health websites, and recommendations to the public, and making consumer and patient information easier to understand and culturally and linguistically appropriate.

There are several provisions in ACA that will help address health literacy:

- A number of requirements to ensure that information about health insurance plans and health insurance exchanges is provided in a way that is linguistically and culturally appropriate. In addition outreach efforts are also required to ensure that all Americans are aware of the benefits to which they are entitled.
- A program that will develop, test, and disseminate educational tools to facilitate shared decision-making and help patients, caregivers, and authorized representatives understand their treatment options.
- A requirement that the Food and Drug Administration evaluate and determine if the use of drug fact boxes which would clearly communicate drug risks and benefits and support clinician and patient decision-making in advertising and other forms of communication for prescription medications is warranted.
- Grants to implement medication management services in treatment of chronic disease. Medication management services will help manage chronic disease, reduce medical errors, and improve patient adherence to therapies while reducing acute care costs and reducing hospital readmissions.

Why this is important for racial and ethnic minorities with chronic illnesses

Low literacy is associated with several adverse health outcomes, including low health knowledge, increased incidence of chronic illness, and less than optimal use of preventive health services. It can compromise health care by hindering the patient-clinician communications, leading to unnecessary, repeat or invasive, costly procedures on the one hand; or missed opportunity to prevent, detect, or treat health problems. Efforts to make patients central to efforts to improve health care and to involve them in self-management of their illness outside of the clinical setting also rely on health literacy.

It is particularly important to address the higher prevalence of health literacy problems in the elderly because they are also most likely to have chronic health conditions. Approximately 80 percent of all seniors have at least one chronic condition and 50 percent have at least two. On average, Medicare beneficiaries use 18.5 prescriptions annually and those with a chronic condition see eight different physicians yearly.⁶⁰

The costs of care for persons with low health literacy are believed to be four times that of the general population.⁶¹ One estimate places cost of low health literacy to the U.S. economy in the range of \$106 billion to \$238 billion annually. This represents between 7 percent and 17 percent of all personal health care expenditures.⁶²

Given the higher rates of poor literacy in racial and ethnic minorities, and the particular language barriers faced by those whose first language is not English, these population groups will benefit disproportionately from efforts to improve health literacy.

Conclusion

As highlighted in a previous report, there are many provisions in ACA and many opportunities that come with their implementation that will bring very real benefits to racial and ethnic minorities and help close the gap on health care disparities.⁶³

This report is specifically focused on the key issues in addressing current racial and ethnic disparities in the prevention, diagnosis, and treatment of chronic illnesses. As such it highlights the needs around five areas:

- Expanded health insurance coverage
- Access to primary care, including preventive services
- Current disparities in the treatment and quality of care that are experienced by racial and ethnic minorities
- The need for culturally competent care, including a greater representation of minorities in the health care workforce
- The role of patient literacy in improving patient care

It is clear that the provisions in ACA are sufficient in variety and scope to address these issues, assuming adequate funding and robust implementation.

A key tenet of health care reform and making the health care system sustainable into the future is the recognition that much of chronic disease conditions can be prevented. This approach recognizes that prevention efforts, combined with better management and coordination of the care delivered to the chronically ill, is an investment that pays off in the medium term with reduced rates of health care services utilization and in the long term with better health outcomes and more productive lives.

Four modifiable health risk behaviors are responsible for much of the illness, suffering, and early death related to chronic diseases:

- Lack of physical activity
- Poor nutrition
- Tobacco use
- Excessive alcohol consumption

These risk factors are common across all population groups, although the prevalence may vary. Rates of obesity, for example, are higher in African Americans and Hispanics than in the general population.

There are many provisions in ACA that both tackle the prevention of chronic disease and encourage the better management of care of the chronically ill, and effective implementation of these will benefit all Americans, regardless of race and ethnicity. Racial and ethnic minorities will only derive maximum benefit from these provisions, however, if information and services are provided in ways that meet the cultural and linguistic needs of the patients. Meeting these needs is not just about improving health care services, it's also about respecting the dignity of minority patients.

Finally, it is imperative that progress towards closing the gap on health care disparities is monitored and measured, that data are collected and evaluated and used to inform further decision making and funding. The ultimate goal is that all Americans, regardless of race or ethnicity, get the health care services they need when they need them, in a manner that ensures quality and equality.

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