

AARP Public Policy Institute
beyond 50.09

Chronic Care:



A Call to Action for Health Reform

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AARP's Public Policy Institute informs and stimulates public debate on the issues we face as we age. Through research, analysis, and dialogue with the nation's leading experts, PPI promotes the development of sound, creative policies to address our common need for economic security, health care, and quality of life.

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Executive Summary



This volume of *Beyond 50* paints a portrait of chronic illness from the consumer perspective. Focus groups and surveys conducted for this study provide a unique look at how patients and caregivers experience our system for treating chronic conditions and disease. The results highlight consumer and caregiver concerns and quality problems that need to be addressed. To realize the potential for more effective care, we offer recommendations for changes aimed at providers, consumers, and caregivers.

AN OVERVIEW OF CHRONIC ILLNESS IN AMERICA

The report starts with a look at the extent of chronic illness in America and its implications for health care delivery and cost. Chapter 1 shows that tremendous changes in medical science, combined with shifts in lifestyle and demographics, have resulted in a rapid rise in the number and proportion of individuals living with one or more chronic illnesses. Older Americans are especially vulnerable to chronic disease. Today more than 70 million Americans ages 50 and older—four out of five older adults—suffer from at least one chronic condition.

The health and financial consequences of chronic illness are profound. People with chronic diseases often have difficulty with basic life activities such as bathing, dressing, or eating. They have significantly higher rates of hospitalization and make more emergency room visits. Their health care spending (shared among patients and payers) is higher than that for people without a chronic disease. A look at specific chronic illnesses shows similar patterns of high spending, above-average use of hospital and emergency room visits, and presence of multiple, often related conditions.

Chapter 2 shows that the experience of chronic disease varies widely. At one end of the spectrum are people with mild chronic diseases who are in other respects healthy and do not have functional limitations. For this healthier group, improving care might mean focusing on engaging, educating, and encouraging individuals to take charge of their own illnesses—in part by adopting healthy behaviors like stopping smoking, eating a healthier diet, and adhering to medication therapies.

At the other end of the spectrum are people with multiple chronic conditions and severe functional limitations, who are more likely to be among the “oldest old.” For this group, improving care requires more than medication adherence and healthy behaviors. These people often use the health care system more intensively and are more at risk for poor coordination of care,

avoidable adverse events, and the loss of important clinical information during transitions among care settings.

Individuals with more severe chronic illnesses are more likely to need supportive services to help them with activities of daily living and to arrange for transportation—and they are more likely to rely on an informal caregiver, such as a spouse, relative, or friend.

Providing high-quality, coordinated care for people with severe chronic illnesses can be a challenge. Providing care for those with barriers to health care, such as people who do not have insurance and people who do not speak the same language as their providers, is an even greater challenge.

Two key opportunities for improvement address care at the two ends of the continuum of disease severity. For people with chronic illness who are otherwise doing well, increasing their actions on their own behalf can influence their outcomes. For those at the other end of the illness spectrum, a focus on transitions is critical. Health care and services that people receive during transitions between settings have a significant effect at a time when they are highly vulnerable.

THE PATIENT EXPERIENCE

Chapter 3 provides the results of two new national surveys conducted for this study—one of people age 50 or older with chronic health conditions who have experienced at least one transition from a health care institution during the past three years and the other of caregivers of people with chronic conditions. The institutional experience may have been as an inpatient in a hospital, nursing home or rehabilitation facility or it could have involved a visit to an emergency room, urgent care setting, or ambulatory survey center.

On average, patient respondents had 3.2 admissions or other major institutional encounters. Caregiver respondents reported that, on average, the people they help support experienced 12 such transitions over three years.

While many people with chronic conditions report fairly good health and express general satisfaction with the health care system, a sizeable group reported significant problems:

- Nearly one in four reported experiencing a medical error and 61 percent of these said they had experienced a major problem as a result.

- One in five (21 percent) reported that their health care providers do not do a good job communicating with each other about their condition or treatment and 20 percent of respondents said their health had suffered as a result.
- Nearly one in six (15 percent) were readmitted within 30 days of discharge from a health care facility.
- One in seven (14 percent) did not get a follow up appointment after discharge or, if they did, it was more than four weeks later.
- One in eight (12.8 percent) respondents reported that health care facility staff did not take their preferences and those of their family or caregiver into account in deciding what their health care needs would be when they left the health care facility.
- One in 11 (9 percent) reported that when they left the health care facility, they did not feel that they clearly understood the warning signs and symptoms they should observe to monitor their health conditions; 7.4 percent did not know who to call when new symptoms arose or their condition got worse.
- Nearly one in five (18 percent) said their transitional care was not well coordinated.

Our survey also investigates whether people who are more engaged in managing their illness experience fewer problems than those who are less engaged. We measured engagement and confidence using a set of survey questions used by a growing number of researchers, known as the Patient Activation Measure (PAM). More than four in ten of our survey respondents reported they are highly activated; more confident and knowledgeable and take more responsibility for their health than those at lower stages on the PAM.

Our survey found that the least activated patients:

- are the most likely to report experiencing problems.
- appeared sicker and had more contact with the health care system than more activated respondents.
- are less likely to look out for themselves and less likely to follow their provider's advice than the most activated respondents.

These findings suggest opportunities for improvement in care coordination, especially during transitions, by better identifying and supporting less activated patients. They also suggest that fostering better patient engagement could be part of a strategy to improve chronic care.

CAREGIVERS REPORT CHALLENGES AND CONCERNS

Among caregivers, concerns about quality of care and poor communication are even more common among those reported in our patient survey.

- About two-thirds of caregivers reported that the health of the person they assisted has gotten worse because he or she did not get the health care attention needed.
- A significant share of caregivers reported concerns about poor communication among clinicians, lack of clinician visits after hospital stays, patients who lack understanding about their medical advice, and patients who receive unnecessary tests and conflicting information.

Our caregiver survey also found that:

- Although everyone in the sample provided care to at least one person (most often a parent or other relative), about 40 percent provide care to more than one person simultaneously.
- Caregivers assist people who are sicker than patients in the patient survey. People with caregivers use the health care system heavily, visiting many different providers frequently over the past three years. These patients rely heavily on their caregivers to provide help with taking medications, making appointments for and getting to physician visits, and understanding medical advice.
- More than two-thirds of caregivers spent more than 10 hours a month providing assistance.

These findings point to both the need and the opportunity to improve care coordination for people with chronic illness, particularly patients who have caregivers. We conclude that reducing the likelihood of poor transitions may require that providers identify and provide support to “high-risk” patients with the following characteristics: more than five chronic conditions, less experience with the health care system, poor health status, need for assistance with patient care coordination activities, and low PAM scores.

These high-risk patients seem to be most vulnerable to poor transitions, are most likely to be readmitted to a health care facility, and are likely to benefit from better support.

ELEMENTS OF GOOD CARE

Experts in chronic care have detailed a vision of good care for people with chronic conditions, which we describe in Chapter 4. However, the best way to implement that vision for the many types of people across different delivery

systems is not yet clear. Some purchasers and health plans have tried various approaches to improving care, with some success in improving outcomes and the efficiency with which care is delivered. We describe some of these programs in this chapter.

However, widespread, sustained improvements in care for people with chronic disease are unlikely unless we address barriers such as the fragmentation of care delivery, poor transitions between and among settings, and misaligned payment incentives that fail to recognize the value of better integration of services.

Poor information systems make these problems worse because it is difficult for providers to track patients over time. Adherence to medications is a key component of effective chronic care management, and a patient's failure (or inability) to take appropriately prescribed medicines is another major barrier to improvement, as is the problem of a patient's taking many drugs with dangerous interactions.

Ideally, our extensive review in this report of the issues around chronic care would lead us to recommend specific models of care, interventions, and financing. Although purchasers and plans are trying approaches that have had some promising results, the evidence is not yet strong enough to draw definitive conclusions about what programs work best.

A STRATEGY FOR IMPROVING CARE

In Chapter 5, we conclude that addressing these barriers requires a multi-pronged strategy that relies on better knowledge, tools, and incentives. For each of these strategies, our recommendations are aimed at providers, family caregivers, and patients—who can play a critical role in managing their own care. Key recommendations for improving coordination of care for people with chronic disease include:

- More testing of care delivery models to find out what works and rapid adoption of better models. We need to gain better knowledge of more effective and efficient care for patients with chronic diseases.
- Incorporating these best practices in clinical preparation and training for providers. Clinicians also need to learn from findings and incorporate the new knowledge into their practice; certification and continuing education programs are ways to learn about best practices.

- Engaging those patients with chronic conditions who are able and willing to participate in their care. Finding the tools to empower them to manage their conditions is essential.
- Supporting family caregivers and engaging caregivers as partners with professionals.
- Encouraging wise use of pharmaceuticals.
- Improving coordination of care through adoption of health information technology and better tools for people to manage their diseases, including tools for informed decision making and group support.
- Improving incentives through changes to payment policy that would reward all providers for working together toward the same goals of improved care and better outcomes.
- Ensuring an adequate workforce and making the most of the workforce we have, including fostering interdisciplinary teams and identifying nurses and pharmacists as team leaders, as appropriate.
- Working for medication affordability because the high cost of some medications can deter patients from adhering to medications that are integral to managing their conditions.



1

Chronic Conditions Among Older Americans

Chronic Illness on the Rise

How Much Do We Spend on
Chronic Conditions?

A Closer Look at Selected Chronic
Conditions



CHRONIC CONDITIONS AMONG OLDER AMERICANS

In this chapter, we describe the extent of chronic illness in America and its implications for health care delivery and cost. Tremendous changes in medical science, combined with shifts in lifestyle and demographics, have resulted in a rapid rise in the number and proportion of individuals living with one or more chronic illnesses. Older Americans are especially vulnerable to chronic disease. Today more than 70 million Americans ages 50 and older—four out of five older adults—suffer from at least one chronic condition.

“More than 70 million Americans ages 50 and older—four out of five older adults—suffer from at least one chronic condition.”

The reasons for the rapid rise in chronic illness are varied. They include the aging of the population, longer life expectancies due to improvements in medical care for infectious diseases, and advances in diagnostic technology and treatment options for many chronic diseases. In addition, changes in lifestyle contribute to higher rates of chronic illnesses such as diabetes, high blood pressure, and heart disease.

The health consequences of chronic illness are extensive. People with chronic diseases often have difficulty with basic tasks such as lifting objects or walking up steps, or daily life activities such as bathing, dressing, or eating. They have significantly higher rates of hospitalization and make more emergency room (ER) visits. Their health care spending (shared among patients and payers) is higher than that for people without a chronic disease.

A closer look at particular chronic illnesses shows similar patterns—high spending, above-average use of hospital and ER visits, and presence of multiple, often related conditions. The particular strategies for successful care management of these conditions will vary with the conditions, but we see several common themes from the patterns of care and the research literature that point to the potential benefit from better coordination and support for people with chronic conditions and their caregivers.

In this chapter, we characterize the impact of various chronic conditions on individuals, their families, and their caregivers. More comprehensive studies of all chronic conditions have been undertaken by other authors (see, for example, Anderson, Horvath, Knickman, Colby, Schear, & Jung, 2002; Centers for Disease Control and Prevention [CDC], 2004; Centers for the Evaluative Clinical Sciences and Dartmouth Medical School, 2006; Alliance for Aging Research, no date). Most of the data and statistics on chronic illness presented in this chapter come from analyses using the 2005 Medicare Expenditure Panel Survey (MEPS)¹ and 1997 and 2006 Medicare claims data.² These analyses were conducted by researchers at the Johns Hopkins

Bloomberg School of Public Health. All references to the 2005 MEPS or 2006 Medicare data indicate findings derived from those analyses. Other data sources are referenced as appropriate.

WHAT IS CHRONIC ILLNESS?

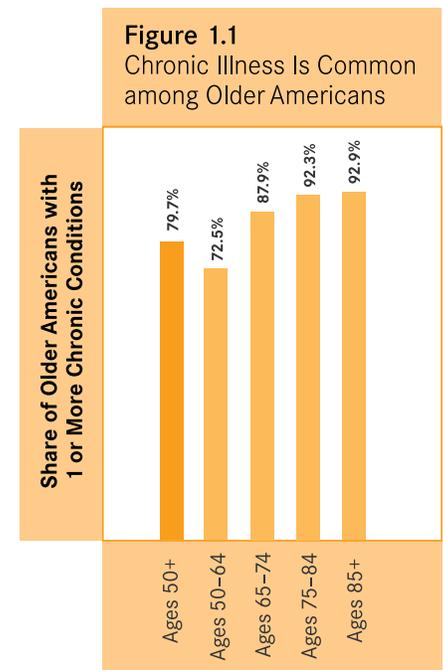
Chronic illnesses are ongoing (usually lasting a year or more), generally incurable illnesses or conditions that require ongoing medical attention and affect a person’s daily life (Hwang, Weller, Ireys, & Anderson, 2001; Anderson & Horvath, 2004; National Center for Health Statistics, 2008). Chronic diseases are often preventable. They are managed with good health care from clinicians and care of their own conditions by people, with help from family members and other informal caregivers. Some of the most prevalent and costly chronic diseases include arthritis, asthma, cancer, cardiovascular (heart) disease, depression, and diabetes, though these are only a few of many illnesses that lower the quality of life of Americans.

CHRONIC ILLNESS ON THE RISE

The latter half of the 20th century was a time of tremendous advances in treating infectious diseases and extending life for all Americans. One side effect of this success is that more Americans ages 50 and older are living with chronic

conditions, often for many years. Changes in the way Americans live, eat, work, and play contribute to increased prevalence of chronic conditions like diabetes, high blood pressure, and heart disease, while improved treatments for such conditions as cancer and congestive heart failure extend life expectancy. A major challenge for our health care system in the 21st century is developing better ways of caring for people with chronic illness.

Today, the statistics on chronic disease are staggering (AHRQ, 2005) (Figures 1.1 and 1.2):



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medical Expenditure Panel Survey, 2005.

Note: Data do not include people who live in institutions.

- More than 70 million Americans ages 50 and older—four out of five older adults—suffer from at least one chronic condition.
- More than half of older adults have more than one chronic condition, and 11 million live with five or more chronic conditions.
- Over 40 percent of all older Americans have high blood pressure, and more than one in four has high cholesterol.
- Almost 20 percent of older Americans suffer from some sort of mental illness.
- Almost 15 percent have diabetes.

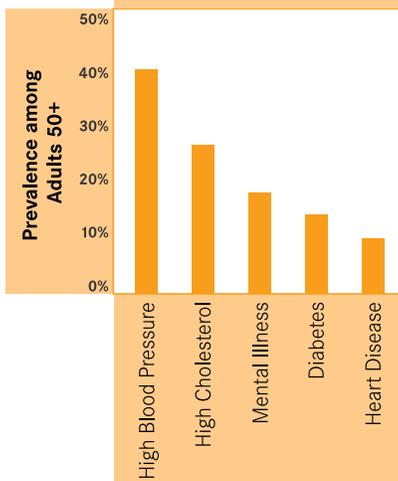
Chronic disease is an increasing burden for older Americans (Figure 1.3):

- The prevalence of diabetes among adults ages 65 and older increased by more than 50 percent between 1997 and 2006 (CMS, 1997, 2006).
- The prevalence of mental illness increased almost 70 percent.³
- All told, the share of Medicare beneficiaries with five or more conditions increased from about 30 percent in 1987 to more than 50 percent in 2002 (Thorpe & Howard, 2006).

WHY ARE CHRONIC CONDITIONS A GROWING PROBLEM?

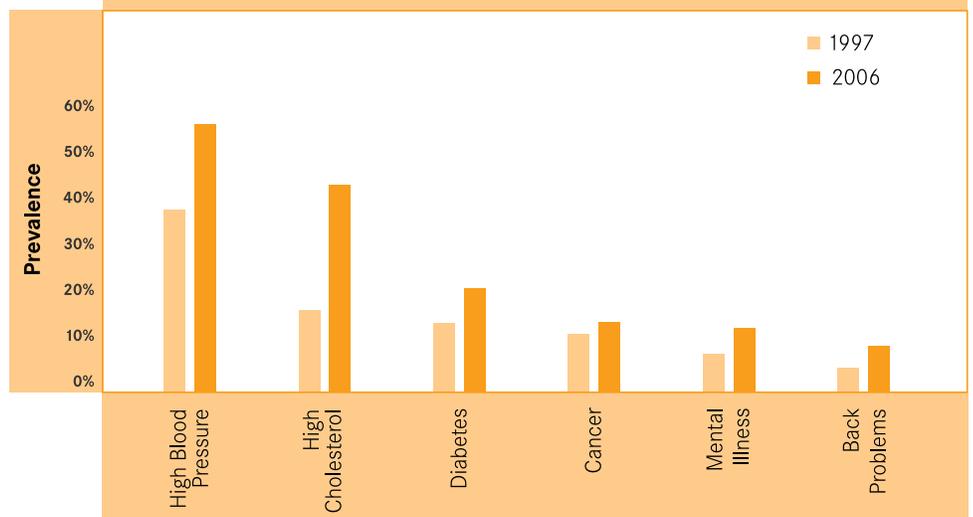
What explains the growing prevalence of many chronic diseases? Several factors are at work. Longer life expectancy is one key factor. The aging of the population also contributes to higher rates of chronic disease. Advances in treatment for chronic illness lead to more people being screened and diagnosed with disease, while changes in clinical practice have broadened the definitions for many chronic conditions. Finally, lifestyle factors, including smoking, changes in exercise habits, and the growing

Figure 1.2
Some Conditions Are Very Common among Older Americans



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medical Expenditure Panel Survey, 2005.
Note: Data do not include people who live in institutions.

Figure 1.3
Many Chronic Conditions Are on the Rise among Medicare Beneficiaries 65+



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medicare claims data.
Note: Prevalence figures shown here are based on Medicare claims data and vary significantly from prevalence data drawn from MEPS data. Medicare claims data are derived from 5 percent sample of beneficiaries over 65 enrolled in Parts A and B, excluding Part C and ESRD.

prevalence of obesity contribute to higher rates of chronic illness.

Longer life expectancy is one important reason why more Americans are developing chronic illness. Improved health care for many acute illnesses and diseases helps to keep people alive longer, thereby raising the chance for them to develop a chronic disease while allowing them to live longer when they do. In the early 1900s the leading causes of death included infectious diseases such as tuberculosis, diphtheria, nephritis, and bronchitis. Today, these diseases have been largely eradicated or are easily treated. Noncommunicable diseases (including many chronic diseases), which accounted for less than 20 percent of deaths in 1900, now

account for more than 80 percent of deaths (Steinbrook, 2004).

As the population ages, we see higher rates of chronic illnesses that appear later in life.

An example of a condition more likely to affect older individuals is diabetes, particularly type 2 diabetes, which typically begins in adulthood and is often associated with obesity. Diabetes, especially type 2, disproportionately affects people over 50 with a prevalence of almost 15 percent in 2005 (Figure 1.4; AHRQ, 2005). Diabetes prevalence (a measure of how common a disease is among the population) rises with age and has increased over time (Figure 1.5). Among Medicare beneficiaries over 65 in the traditional fee-for-

service program, the prevalence was over 22 percent in 2006, up from 14.9 percent in 1997, an increase of over 50 percent. Similarly, the prevalence rate for hypertension also increases with age (CDC, National Center for Health Statistics, 2007). Middle-age Americans (ages 55–65) face a lifetime risk of 90 percent of developing hypertension at some time during the rest of their lives (Vasan et al., 2002).

Another factor contributing to the rise of chronic disease is greater

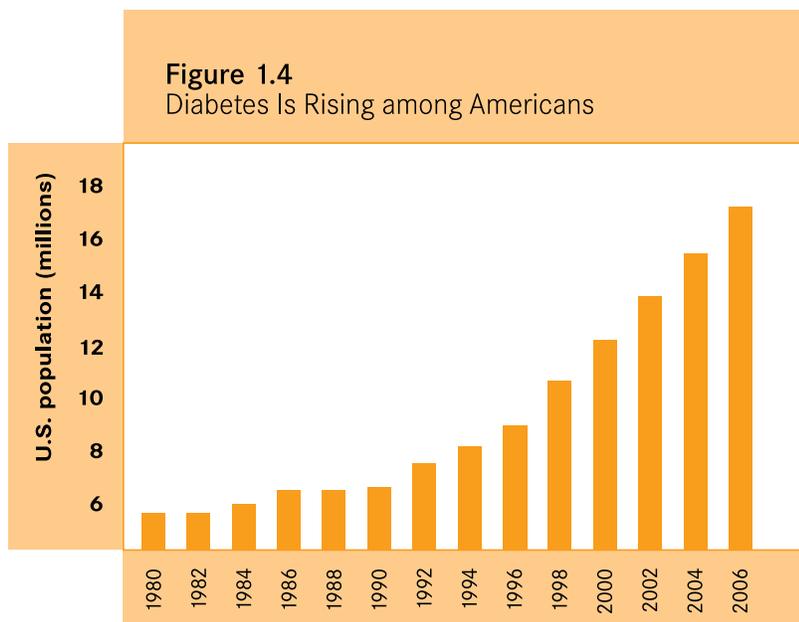


Figure 1.4
Diabetes Is Rising among Americans
Source: CDC Diabetes Surveillance System.
Note: Includes all forms of diagnosed diabetes.

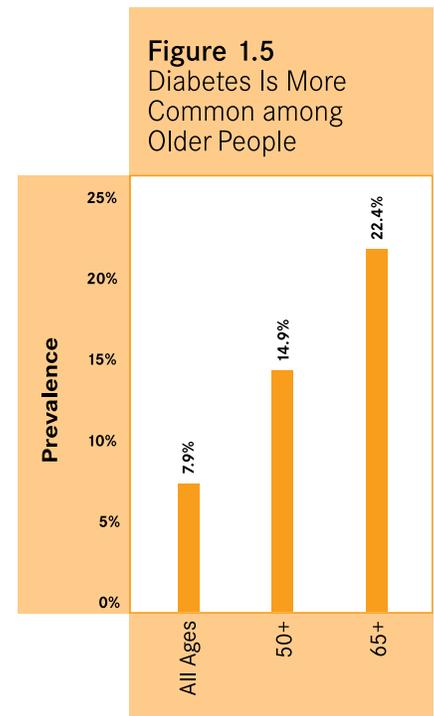


Figure 1.5
Diabetes Is More Common among Older People
Source: Johns Hopkins Bloomberg School of Public Health analysis of Medicare claims data, 2006, and Medical Expenditure Panel Survey, 2005.

Note: Medicare claims data are derived from 5 percent sample of beneficiaries over 65 enrolled in Parts A and B, excluding Part C and ESRD.

awareness by both providers and the public, coupled with advances that make treating the diseases easier. Treatment advances allow providers to diagnose illness and identify people who might be helped by medications or therapies, while public awareness of chronic conditions leads to more people requesting testing and treatment. For instance, public awareness of hypertension has increased from about 50 percent of the population in 1976 to 70 percent in 2000 (National Institutes of Health, National Heart, Lung, and Blood Institute, 2003). Increasing awareness has encouraged greater diagnosis and treatment of hypertension.

Other factors have also expanded the percentage of the population who are either potentially or actually under treatment for hypertension and influenced the age at which hypertension may first be detected. Changes in clinical practice have contributed to an increase in the reported prevalence of hypertension (Joint National Committee, 2003). Guidelines for diagnosing hypertension have been changing, leading prescribers to treat less severe forms of the condition (Ostchega et al., 2007). Although anti-hypertensive drugs have been available for years, newer medications for high blood pressure have become available and they have fewer side effects and greater convenience (Staessen, Wang, & Lutgarde, 2001). As a result, from 1997 to 2006, the percentage of Medicare beneficiaries over 65 who have been diagnosed with hypertension has increased by almost 50 percent (39.5 percent vs. 58.1 percent).

High cholesterol presents a similar case. The advent of statins in the early 1990s offered more effective treatments for high cholesterol with fewer side effects.⁴ As the benefits of statins became better proven, they became more widely known. Public awareness of high cholesterol increased from less than 40 percent of the population before 1988 to more than 60 percent by 2004 (Hyre et al., 2007). Greater awareness among providers and the public encouraged more diagnosis and treatment of high cholesterol. In addition, changing treatment guidelines (e.g., lower target levels for low density lipoproteins, or LDL cholesterol), clinical practice patterns (e.g., more intensive management of high-risk patients), and the availability of generic versions of these medications accelerated these trends (National Cholesterol Education Program Expert Panel, 2001). As a result, from 1997 to 2006, the percentage of Medicare beneficiaries over 65 who have been diagnosed with high cholesterol has increased by more than 150 percent (17.7 percent vs. 44.9 percent).

Finally, high rates of smoking, obesity, and unhealthy behaviors contribute to increased rates of several chronic illnesses, including COPD,⁵ diabetes, and cancer. Researchers estimate that obese people have 67 percent more chronic conditions than normal-weight individuals, while smoking increases chronic illness by 25 percent (RAND Health, 2002). With obesity rates growing rapidly (by more than 60 percent between 1991 and 2000), the prevalence of chronic illness will continue to rise.

People with chronic illness today report being in better health than people 20 years ago. In part due to early diagnosis, people on Medicare who are treated for five or more conditions reported being in good or excellent health in nearly 60 percent of cases in 2002, almost double the 33 percent of cases reporting similar health status in 1987 (Thorpe & Howard, 2006).

Not all chronic illnesses are on the rise. The prevalence (unadjusted for age or sex) of some chronic conditions has not changed substantially or has even decreased over the past decade. Some conditions that are becoming less prevalent include congestive heart failure (down 4.4 percent between 1997 and 2006), dementia (down 10.0 percent), hip fracture (down 0.9 percent), and kidney disease excluding end-stage renal disease (ESRD) (down 4.9 percent) (CMS, 1997, 2006).

WHO IS MOST LIKELY TO HAVE CHRONIC DISEASE?

Chronic illness affects everyone, but some demographic groups are especially vulnerable. Older Americans are more likely to suffer from certain chronic illnesses, while minorities are at greater risk for conditions like diabetes, stroke, and high blood pressure. Many 50+ Americans with chronic diseases are low-income older adults.

It is not surprising that the burden of chronic illness grows as a person ages. While just under half of Americans ages 50–64 have a chronic condition, nine out of 10 Americans ages 75 and older have at least one, and more than 20 percent suffer from five or more chronic illnesses. The rates of heart disease, high blood pressure, cancer, and mental illness are all higher in older age cohorts. The risk of heart disease is three times higher in someone 75+ than in a person ages 50–64. Similarly, the risk of high blood pressure is 66 percent higher for those 75 to 84 years old than for those 50 to 64 years old.

Interestingly, the “oldest old,” those ages 85 and above, are not significantly sicker than those ages 75–84, a finding that other researchers have attributed to survival of the healthiest individuals. Dementia

is an important exception to this pattern: the risk of dementia rises steadily with age, from a prevalence of less than 1 percent in adults ages 50–64 to 16 percent in those ages 85 and above (AHRQ, 2005).

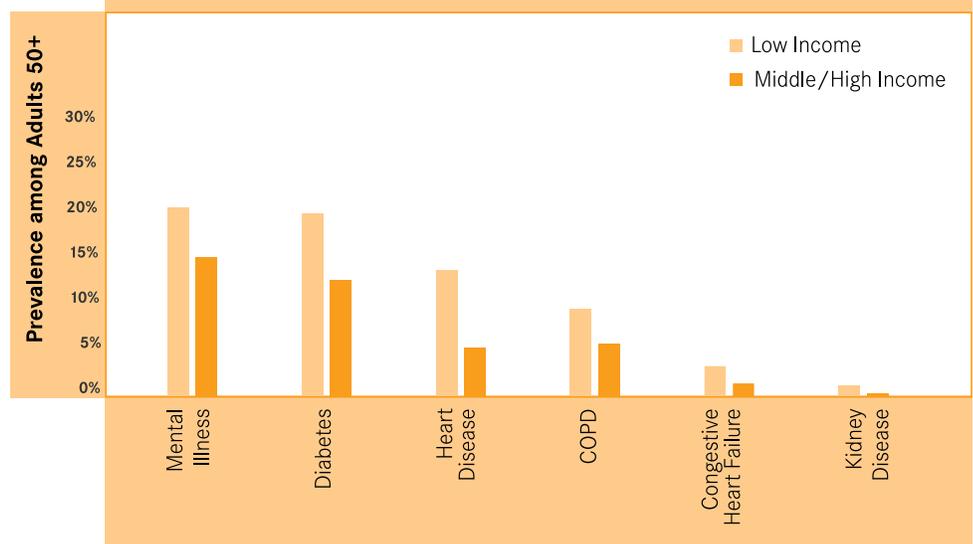
Not all chronic illnesses are so closely associated with increased age. Kidney disease, rheumatoid arthritis, and COPD are examples of chronic conditions that often afflict individuals younger than 50 and do not become significantly more prevalent with age.

The burden of chronic disease is greater for low-income older adults who have higher rates of many conditions, including kidney disease, congestive heart failure,

heart disease, mental illness, and diabetes, than for middle- or upper-income older adults (Figure 1.6).

Minorities also bear a disproportionate burden of certain chronic diseases, including high blood pressure, diabetes, and stroke. These conditions are associated with a number of complications that can impact physiological, functional, and cognitive well-being. In 2005, African Americans over age 50 were about twice as likely as whites to have diabetes, while older Hispanics had a 78 percent higher prevalence of the disease than whites. Diabetes-related mortality rates for African Americans,

Figure 1.6
Many Chronic Diseases Are More Common among Low-Income Seniors



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medical Expenditure Panel Survey, 2005.

Note: Data do not include people who live in institutions.

Hispanic Americans, and American Indians are higher than those for non-Hispanic whites.

Minorities are also more likely to suffer from diabetes-related complications such as kidney disease, lower limb amputation, and retinopathy.⁶ These are the very outcomes that better care coordination and preventive services are designed to reduce or eliminate.

For example, Mexican Americans are 4.5 to 6.6 times and non-Hispanic blacks are 2.6 to 5.6 times more likely to experience diabetes-related end-stage renal disease than their white counterparts (American Diabetes Association, no date). The same two groups are also 1.8 times (Mexican Americans) and 2.7 times (non-Hispanic blacks) more likely to experience diabetes-related amputations (American Diabetes Association, no date). Mexican Americans are almost twice and non-Hispanic blacks are almost 50 percent more likely to develop vision problems related to diabetes as non-Hispanic whites (American Diabetes Association, no date).

Stroke is another condition that disproportionately affects African Americans. The prevalence of stroke is almost double for older African Americans (4.6 percent) compared with whites (2.4 percent). Older Hispanics have a lower rate of stroke (1.9 percent) than other

ethnic groups. The death rate from stroke per 100,000 is 48.1 for white males, 47.2 for white females, 74.9 for black males, and 65.5 for black females (Rosamond et al., 2008).

WHAT DO CHRONIC CONDITIONS DO TO HEALTH?

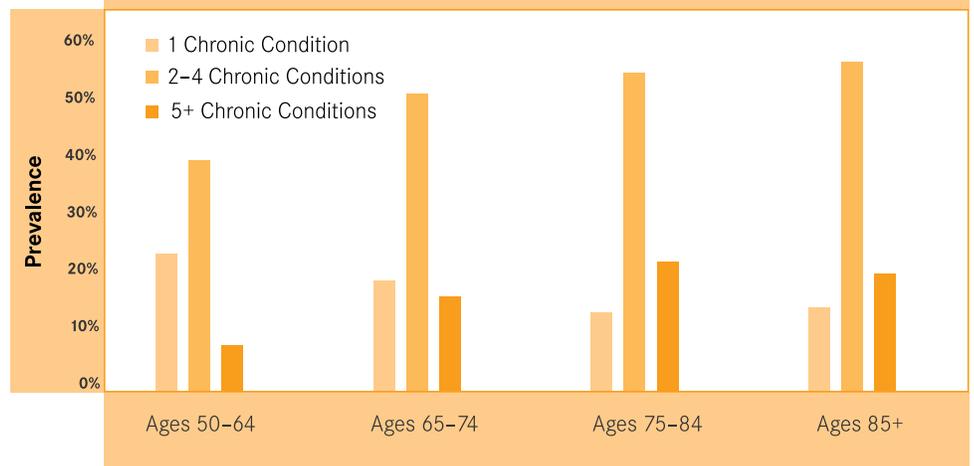
What does it mean to have a chronic condition? The consequences of chronic disease include increased health risks, reduced quality of life, and greater financial costs for people and those who help pay bills (Medicare, Medicaid, insurance companies, and employers).

Chronic illness is rarely confined to a single disease. About 20 percent of the 50+ population has just one chronic condition, while about

32 percent of the 50+ population has between two and four chronic illnesses. Almost 7 percent of older Americans suffer from five or more chronic conditions. The risk of having multiple conditions increases with age. While the risk of having any chronic conditions increases from 70 percent to 92 percent between ages 50 and 85+, the risk of having five or more chronic conditions almost triples, from 8 percent for those ages 50–64 to 21 percent for those ages 85+ (Figure 1.7).

In addition, some chronic illnesses carry a higher risk of co-morbidity than other conditions. People with congestive heart failure, kidney disease, and stroke are much more likely to have five or more other

Figure 1.7
Many Older Americans Have Multiple Chronic Conditions



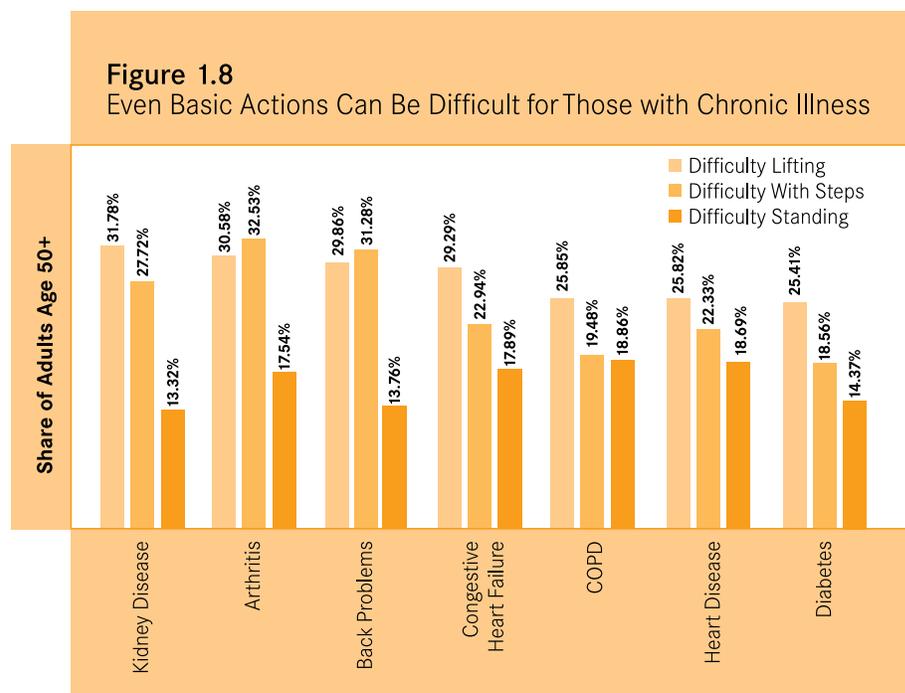
Source: Johns Hopkins Bloomberg School of Public Health analysis of Medical Expenditure Panel Survey, 2005.

Note: Data do not include people who live in institutions.

chronic conditions than people with arthritis, mental illness, or cancer.

Chronic illness takes a toll on many of the core functions and activities of daily life. People with chronic illness often need help performing basic activities of daily living, or ADLs, like bathing, eating, dressing, toileting, or getting out of bed or a chair. One-third of people with kidney disease require assistance with at least one of these ADLs. Other tasks, such as standing for extended periods, lifting, or going up steps, also become more difficult for those with chronic conditions. More than half of people with congestive heart failure, dementia, arthritis, kidney disease, or back problems have difficulty with at least one core function (Figure 1.8; AHRQ, 2005).

Older Americans with a chronic condition are far more likely to be hospitalized than the average population ages 50+. Overall, only about one in 10 older Americans has a hospital stay in a given year. In contrast, about half of those with kidney disease have a hospitalization, and more than 40 percent of those with congestive heart failure are hospitalized annually. Even high blood pressure, back problems, and high cholesterol increase the risk of hospitalization. Not surprisingly, most at risk are those with multiple chronic conditions. For a person



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medical Expenditure Panel Survey, 2005.

Note: Data do not include people who live in institutions.

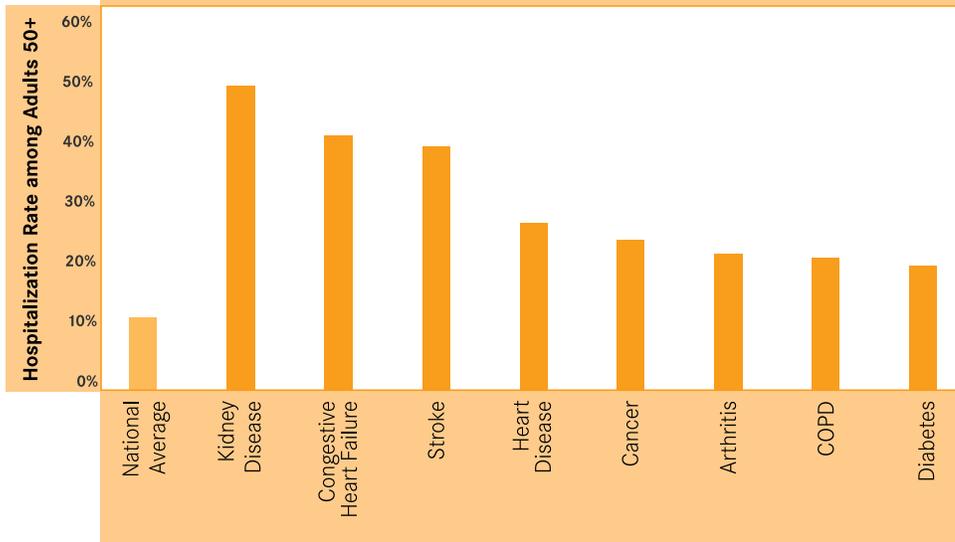
with COPD, for example, the likelihood of being hospitalized during the year is about seven times greater for a patient with five or more conditions than for a patient who has only COPD. A diabetic with five or more chronic conditions is twice as likely as a diabetic with only one or two conditions to be hospitalized (Figure 1.9; (AHRQ, 2005).

In addition to raising the risk of hospitalization, chronic illness leads to higher rates of home health care use, clinician visits, and medication use. While only about 6 percent of older Americans use home health care during a year on average, about a quarter

of people with congestive heart failure or kidney disease use home health, and more than 10 percent of people with COPD, diabetes, stroke, mental illness, cancer, heart disease, or arthritis require such care in a year (AHRQ, 2005).

Ultimately the health consequences of chronic disease add up to lower life expectancy. A person who reaches age 65 without a chronic condition can expect to live another 22 years—to about age 88. In contrast, a person who reaches age 65 with one or two chronic conditions can expect to live another 20 years, while a person with three or more chronic conditions can expect to live

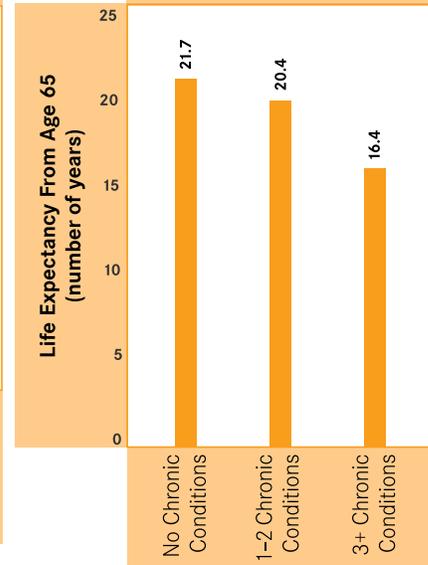
Figure 1.9
Chronic Conditions Lead to Higher Risk of Being Hospitalized



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medical Expenditure Panel Survey, 2005.

Note: Data do not include people who live in institutions.

Figure 1.10
Chronic Illness Reduces Life Expectancy



Source: Joyce, Keeler, Shang, & Goldman, 2005.

another 16 years, to about age 81 (Figure 1.10; Joyce, Keeler, Shang, & Goldman, 2005).

HOW MUCH DO WE SPEND ON CHRONIC CONDITIONS?

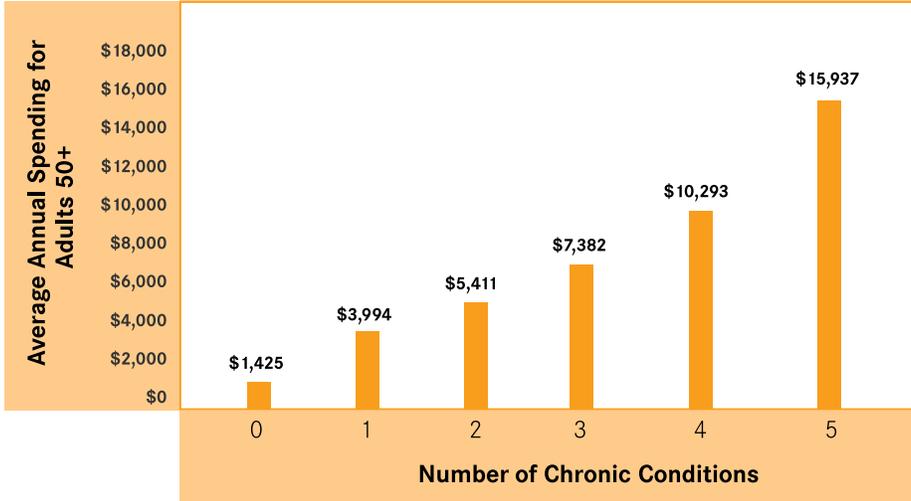
Chronic conditions are costly for patients, payers, and public programs. Average health care spending for Americans 50+ was about \$6,400 in 2005. Spending for those who had no chronic illnesses averaged \$1,425, while spending on people with five or more conditions averaged almost \$16,000 (Figure 1.11; AHRQ, 2005).⁷ For older Americans with kidney disease, average spending was more than \$37,000, almost six times the overall average for Americans

ages 50+. Even people with high cholesterol and high blood pressure have spending that is 30 percent or more above the national average. Nine of the top 10 highest-cost health conditions in the United States are chronic,⁸ and 85 percent of all health care spending in 2004 was for people with chronic conditions (Figure 1.12).

Following trends in utilization, spending is closely associated with the number of chronic conditions a person has. With the exception of cancer, average annual spending among people with four or more other conditions is far higher than average spending for those with no other conditions. Among

people who have suffered a stroke, more than 60 percent of annual group spending is concentrated in those who have five or more other conditions that compound the difficulties of stroke recovery. Spending for congestive heart failure, kidney disease, back problems, and COPD is also highly concentrated on those people who have multiple chronic conditions. An exception to the general rule of more conditions leading to higher spending is cancer, where average spending is fairly equal across all people, regardless of the total number of chronic conditions. This may be due to the high cost of cancer treatments

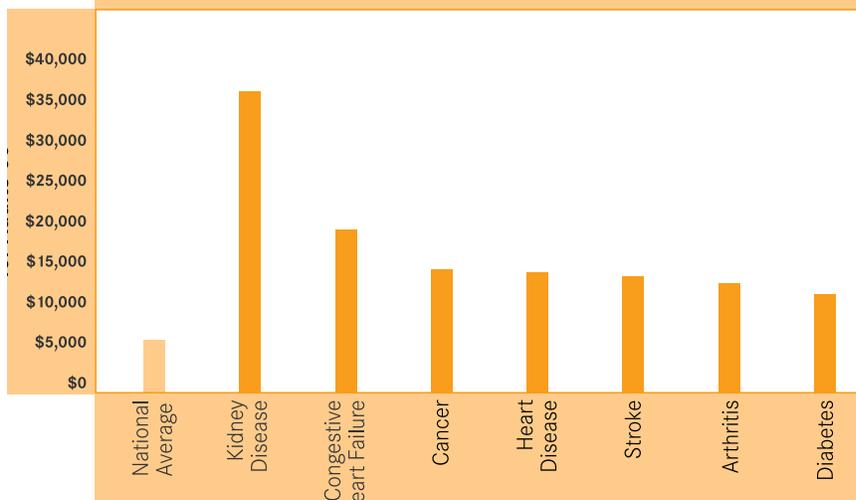
Figure 1.11
Health Spending Increases with the Number of Chronic Illnesses



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medical Expenditure Panel Survey, 2005.

Note: Data do not include people who live in institutions.

Figure 1.12
Health Care Spending for Older Americans with Selected Chronic Conditions Is Higher Than Average



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medical Expenditure Panel Survey, 2005.

Note: Data do not include people who live in institutions.

such as chemotherapy, radiation, and pharmaceuticals.

These costs add up quickly. Total health care spending for a person with one or two chronic conditions at age 65 is about \$14,500 (in 2005 dollars) more than a person who has no chronic conditions at age 65. Total spending for someone with three or more chronic conditions at age 65 will be more than \$41,000 more, even after accounting for the shorter life expectancy associated with having multiple chronic conditions. How much a particular condition adds to total spending depends both on the cost of treatment and the impact that disease has on life expectancy. Over a lifetime, diabetes is more costly than cancer (\$15,052 in additional spending vs. \$13,503), and high blood pressure is more expensive than stroke (\$11,143 vs. \$4,397) (Figure 1.13) (Joyce, Keeler, Shang, & Goldman, 2005).

In the Medicare program, treatment for hypertension cost \$163 billion in 2006.⁹ Per-patient spending for the most costly conditions has increased by between 20 percent and 36 percent over the last decade, and total program spending for these conditions has increased by between 32 percent and 81 percent (Table 1).

A CLOSER LOOK AT SELECTED CHRONIC CONDITIONS

Researchers have observed that people with multiple chronic conditions are high users of health care services and account for a disproportionate share of health care spending (Wolff, Starfield, & Anderson, 2002). But these high figures mask different patterns in spending and health care needs that follow from different clinical needs for different illnesses, severity of illness, and stage of illness. Nonclinical factors, such as functional ability, family support, informal caregiver availability, financial circumstances, and community support services, also influence people's ability to manage their condition(s).

To explore this variation, we look at patterns of care for specific conditions and groups of related chronic conditions to identify how people with chronic conditions use health care services and where there might be opportunities for improving coordination of services for these people. In Chapter 4, we describe models of care for chronic diseases that attempt to address the issues identified here, and discuss the barriers to more widespread adoption of innovative models of care for chronic illness.

Table 1. Top Chronic Conditions for Medicare 65+ Based on Aggregate Cost, 2006

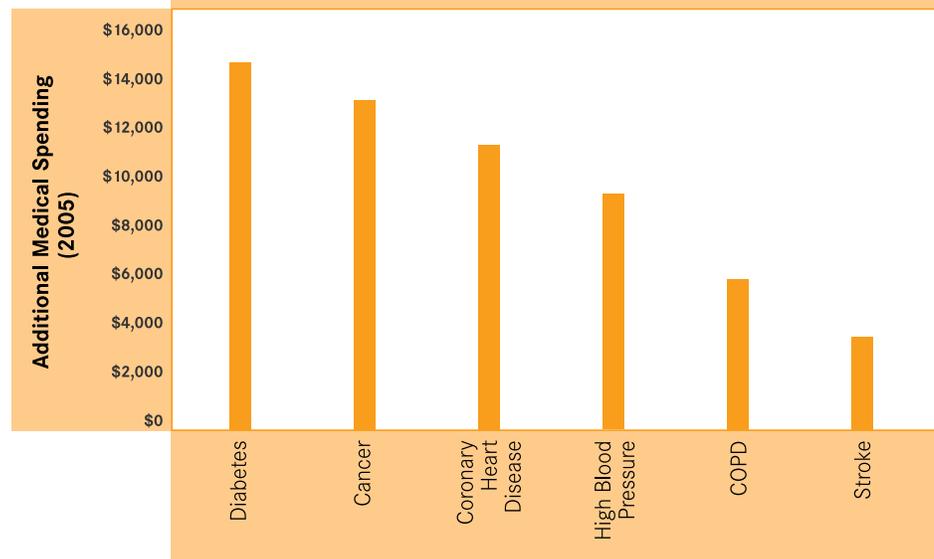
Chronic Condition	Parts A & B Total cost	Change (1997–2006)	Parts A & B Cost/Case	Change (1997–2006)
Hypertension	\$163.2 B	81%	\$10,653	21%
Heart Disease (other)	\$130.4 B	65%	\$15,358	24%
Cholesterol	\$104.3 B	52%	\$ 8,820	36%
Arrhythmias	\$74.9 B	37%	\$19,509	24%
Diabetes	\$74.6 B	37%	\$12,643	20%
CHF	\$72.2 B	36%	\$25,841	31%
Mental Conditions	\$71.3 B	36%	\$19,624	26%
COPD	\$63.9 B	32%	\$18,511	27%

Source: Johns Hopkins Bloomberg School of Public Health analysis of Medicare claims data.

Note: Medicare claims data are derived from 5 percent sample of beneficiaries over 65 enrolled in Parts A and B, excluding Part C and ESRD.

Figure 1.13

Additional Lifetime Medical Spending for Medicare Beneficiaries with Chronic Conditions at Age 65



Source: Joyce, Keeler, Shang, & Goldman, 2005.

Note: Shows the additional spending for that condition compared with no disease.

CHRONIC BONE CONDITIONS

Many people over 50 have a chronic bone condition such as osteoporosis, back problems, or arthritis. People with a chronic bone condition are often affected by more than one bone condition and may have other chronic conditions as well. The prevalence of chronic bone conditions has increased substantially among Medicare beneficiaries over 65 in

the traditional program from 1997 to 2006 (Figure 1.14).

To some extent, these conditions may be related to each other. For instance, osteoporosis may lead to back problems and can lead to acute and sometimes catastrophic events, like a hip fracture. Arthritis, both osteoarthritis and rheumatoid arthritis,¹⁰ can cause joint pain and stiffness and may limit mobility and function. Without proper medical care, rheumatoid arthritis causes permanent disability in three to five years among 20 percent to 30 percent of people who have the disease and reduces

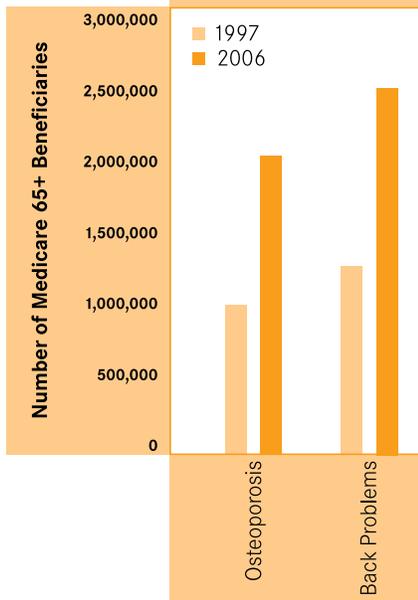
life expectancy by as much as 15 years (*New York Times*, 2008).

Over the long term, in an effort to reduce pain and increase mobility, many people with osteoarthritis and rheumatoid arthritis undergo risky and expensive artificial joint replacements, such as hips and knees.

People with a primary diagnosis of one of these chronic bone conditions use many health services.

As shown in Figure 1.15, more than 40 percent of people with chronic bone conditions tend to have ER visits and hospital admissions,

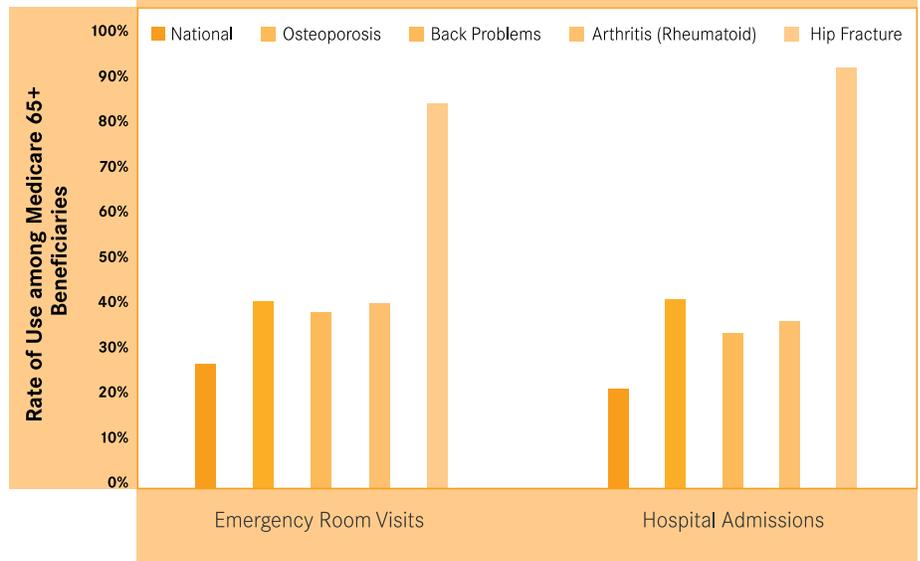
Figure 1.14
Chronic Bone Conditions Becoming More Common among Medicare Beneficiaries 65+



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medicare claims data.

Note: Medicare claims data are derived from 5 percent sample of beneficiaries over 65 enrolled in Parts A and B, excluding Part C and ESRD.

Figure 1.15
People with Chronic Bone Conditions Have Higher Than Average ER and Hospital Use



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medicare claims data.

Note: Medicare claims data are derived from 5 percent sample of beneficiaries over 65 enrolled in Parts A and B, excluding Part C and ESRD.

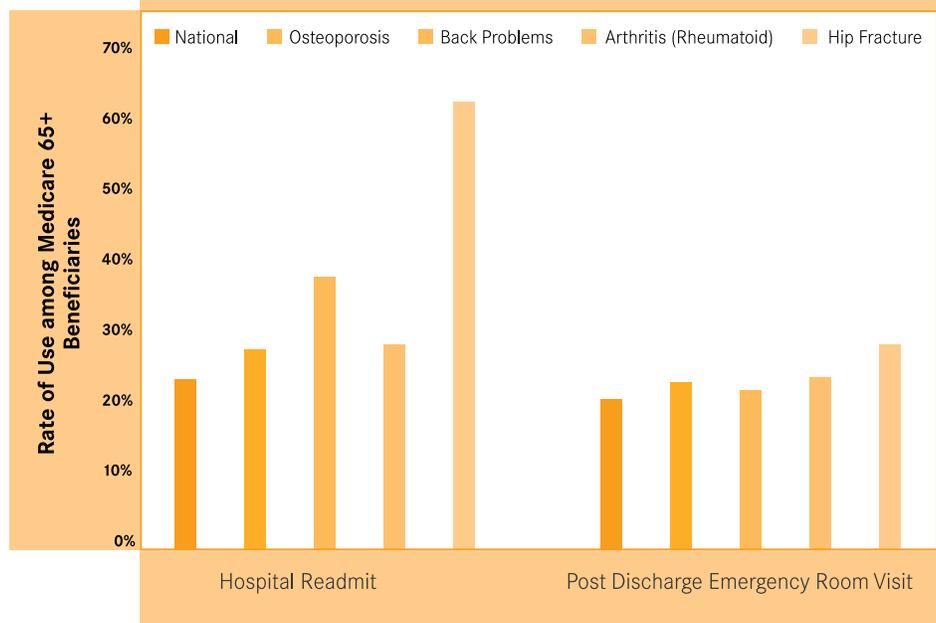
compared with fewer than 30 percent for the national average of Medicare beneficiaries over 65 in the traditional program.

In some cases, appropriate care management and coordination may reduce the need for back surgery, hip fracture repair, and joint replacement. Some encounters with the health care system, such as ER visits soon after discharge and rehospitalizations, could be avoided entirely. Appropriate diagnosis, treatment, and management of osteoporosis and osteoarthritis or rheumatoid arthritis can influence the course of these chronic conditions by slowing or arresting bone deterioration, loss of mobility, and pain associated with these chronic conditions (Arthritis Foundation, www.arthritis.org; National Osteoporosis Foundation, www.nof.org). In some cases, it may be possible to reduce serious complications associated with these conditions, such as fractures, through preventive measures, such as fall reduction programs. Falls account for 10 percent of ER visits and 6 percent of hospitalizations among people over 65. A recent study found that a combination of risk assessment, patient education, and adjustments in treatment could substantially reduce the risk of serious falls, fractures, ER visits, and hospitalization (Tinetti et al., 2008).

As indicated in Figure 1.16, 39 percent of Medicare beneficiaries over age 65 with back problems who were hospitalized were readmitted within 30 days, and 23 percent had an ER visit within 30 days of discharge. However, only 70 percent of these people had a clinician visit within 30 days of discharge. These relatively high readmission and return ER visit rates suggest that some of this care could have been provided in more appropriate settings, such as a provider’s office or clinic, or avoided entirely.

Targeting people with chronic bone conditions for more intensive clinical management and care coordination may offer opportunities to improve outcomes and find savings. For instance, a study comparing management of care for people with rheumatoid arthritis found that the cost of care delivered by a clinical nurse specialist was lower with the same clinical outcomes for care as that delivered by a multidisciplinary team in an inpatient hospital setting or an outpatient setting (van den Hout et al., 2003).

Figure 1.16
People with Chronic Bone Conditions Have Higher Than Average Potentially Avoidable Encounters



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medicare claims data.

Note: Medicare claims data are derived from 5 percent sample of beneficiaries over 65 enrolled in Parts A and B, excluding Part C and ESRD.

OSTEOPOROSIS

Osteoporosis, or “weak bones,” is a chronic condition characterized by low bone mass and structural deterioration of bone tissue leading to bone fragility and increased susceptibility to fractures (National Osteoporosis Foundation, www.nof.org). It is estimated that osteoporosis affects about 10 million Americans over age 50, and another 34 million have low bone mass. Osteoporosis is a silent disease until a fracture occurs. About one in two women and one in four men over 50 will have an osteoporosis-related fracture during their remaining lifetimes. Fractures due to osteoporosis are most likely to occur in the hip, spine, and wrist, but any bone can be affected (Office of the Surgeon General, 2004).

Among Medicare beneficiaries over age 65, about 8 percent had a primary diagnosis of osteoporosis in 2006, up from about 4 percent in 1997. It is unclear how much of this increase may have been related to increased incidence of disease and how much may have been related to increased awareness and treatment. In 2006, about 65 percent of people on Medicare with osteoporosis had five or more chronic conditions (including osteoporosis). People with osteoporosis were more commonly affected by other bone-related problems. For example, these beneficiaries were 1.7 times more likely to have osteoarthritis and 1.5 times more likely to have back problems than average (CMS, 2006). People with bone-related problems often have

other conditions, such as COPD, cancer, rheumatoid arthritis, or kidney disease, that may lead to or aggravate osteoporosis by depleting calcium or otherwise upsetting the balance of bone regulatory hormones (Office of the Surgeon General, 2004).

People with osteoporosis use many health services (see Table 2). Experts have suggested that health professionals can take a number of steps to improve bone health, such as identifying and treating people at high risk for bone disorders and educating people about how to prevent and manage bone disease (Office of the Surgeon General, 2004).

Table 2. Medicare Utilization and Spending for Chronic Conditions, 2006								
	Office Visits (Avg. number)	ER Visits (proportion)	Hospital Admissions (proportion)	Average Length of Stay (days)	Readmissions within 30 days (proportion)	ER Visits within 30 days of Discharge (proportion)	Average Medicare Spending per Case (dollars)	Total Medicare Spending on Condition (dollars)
National Average	17.3	27.5%	22%	2.2	24%	21%	\$7,613	n/a
Osteoporosis	26	41%	38%	4.0	28%	24%	\$12,816	\$27 billion
Hip Fractures	46	85%	93%	18.5	64%	29%	\$45,600	\$558 million
Arrhythmia	34	55%	54%	7.0	31%	29%	\$19,500	\$75 billion
Stroke	32	55%	56%	9.8	35%	29%	\$21,000	\$31 billion
Cancer	29	36%	34%	3.8	27%	24%	\$14,000	\$57 billion

Source: Johns Hopkins Bloomberg School of Public Health analysis of Medicare claims data.

Note: Medicare claims data are derived from 5 percent sample of beneficiaries over 65 enrolled in Parts A and B, excluding Part C and ESRD.

CHRONIC CARDIOVASCULAR CONDITIONS

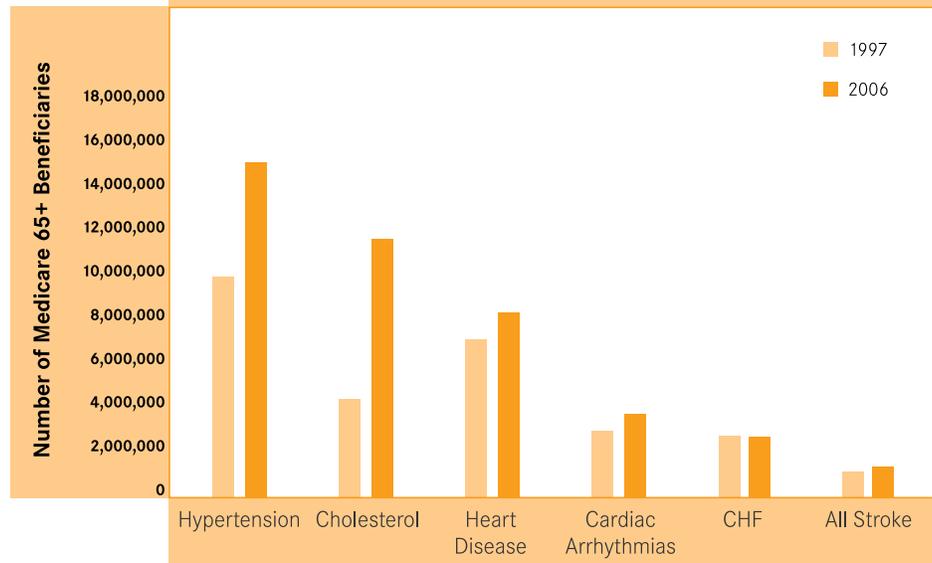
Chronic cardiovascular conditions, such as hypertension, high cholesterol, congestive heart failure, cardiac arrhythmias, other heart disease, and stroke, also affect many people over 50. People are often affected by more than one cardiovascular condition. The number of Medicare beneficiaries over 65 with chronic cardiovascular conditions increased substantially from 1997 to 2006 (Figure 1.17).

These conditions are sometimes related to each other. For instance, hypertension may lead to heart disease, heart attack, and stroke. Cardiac arrhythmias can also lead to stroke, heart failure, and sudden death (National Heart, Lung, and Blood Institute, Diseases and Conditions, www.nhlbi.nih.gov).

As shown in Figures 1.18 and 1.19, people with some chronic cardiovascular conditions (i.e., congestive heart failure, arrhythmias, other heart disease, and stroke) are more likely to have ER visits and hospital admissions, compared with the national average of Medicare beneficiaries over 65 in the traditional program.

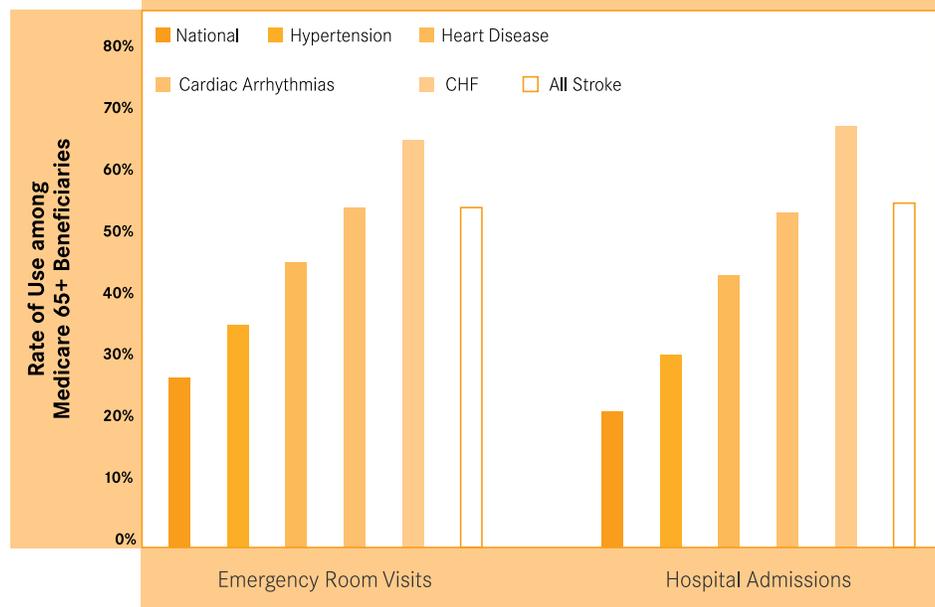
Appropriate diagnosis, treatment, and management of chronic cardiovascular conditions can influence the course of these chronic conditions. As we

Figure 1.17
Chronic Cardiovascular Conditions Are Becoming More Common among Medicare Beneficiaries



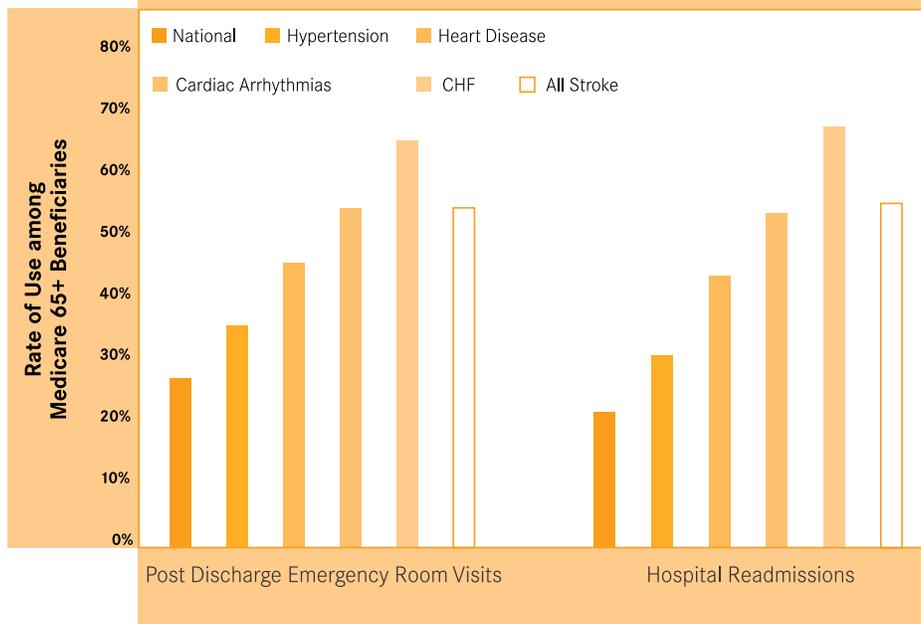
Source: Johns Hopkins Bloomberg School of Public Health analysis of Medicare claims data.
Note: Medicare claims data are derived from 5 percent sample of beneficiaries over 65 enrolled in Parts A and B, excluding Part C and ESRD.

Figure 1.18
People with Chronic Cardiovascular Conditions Have Higher Than Average Emergency Room and Hospital Use



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medicare claims data.
Note: Medicare claims data are derived from 5 percent sample of beneficiaries over 65 enrolled in Parts A and B, excluding Part C and ESRD.

Figure 1.19
 People with Chronic Cardiovascular Conditions Have Higher Than Average Potentially Avoidable Encounters



Source: Johns Hopkins Bloomberg School of Public Health analysis of Medicare claims data.

Note: Medicare claims data are derived from 5 percent sample of beneficiaries over 65 enrolled in Parts A and B, excluding Part C and ESRD.

describe in the following sections, targeting people with chronic cardiovascular conditions for more intensive clinical management and care coordination may offer opportunities to improve outcomes and find savings.

ARRHYTHMIAS

Cardiac arrhythmias, problems with the rhythm or rate of heartbeats, constitute a serious chronic condition that may lead to fainting, heart attack, stroke, and sudden death. Arrhythmias are more common among older adults. In 2005, about 4 percent of the U.S.

population over 50 had some type of arrhythmia. Among Medicare beneficiaries over 65 in the traditional program, the prevalence of arrhythmias was more than 14 percent in 2006, up from 12 percent in 1997 (CMS, 1997, 2006).

More than 48 percent of people over 50 with cardiac arrhythmias have four or more additional chronic conditions, and about 31 percent have impairments in three or more daily activities. Among Medicare beneficiaries over 65, more than 74 percent had five or more chronic conditions (including arrhythmia) in 2006.

Other chronic conditions affecting people over 50 with arrhythmias are often cardiovascular in nature, such as hypertension (66 percent) and other heart disease (18 percent). Medicare beneficiaries over 65 with arrhythmia as a primary diagnosis are more commonly affected than average Medicare beneficiaries by co-morbidities, particularly those related to cardiovascular conditions, such as hypertension, congestive heart failure, and other heart disease. In addition, for reasons not well understood, some coexisting chronic conditions such as thyroid conditions may contribute to arrhythmias (National Institutes of Health, National Heart, Lung, and Blood Institute, 2003).

For people with arrhythmias, experts recommend a variety of patient education and self-management approaches to manage this chronic condition and reduce risk of complications, such as keeping a record of changes in pulse rate, keeping all medical appointments, maintaining a list of current medications, reporting symptoms and side effects promptly, and following the provider's advice regarding treatment and healthy lifestyle (National Institutes of Health, National Heart, Lung, and Blood Institute, 2003).

People with arrhythmias have frequent encounters with the

health care system. Many people with arrhythmia undergo procedures related to pacemakers or implantable defibrillators to treat the condition, which frequently require ER visits or hospitalization. People with arrhythmia have above-average rates of potentially avoidable encounters, such as hospital readmission and post-discharge ER visits. Among Medicare beneficiaries over 65 in the traditional program, the average program cost per arrhythmia patient (primary diagnosis) was about \$19,500, which accounted for Medicare spending of almost \$75 billion in 2006.

Programs that improve adherence to evidence-based guidelines for cardiovascular conditions can improve coordination and quality of care and improve clinical outcomes for major cardiovascular diseases (Ellrodt et al., 2007).

POST-STROKE MANAGEMENT

A stroke, or cerebrovascular accident, is an acute brain injury caused by a clot or bleeding that can lead to serious and lasting impairments, such as paralysis, impaired brain function, and death. Stroke is the third leading cause of death and is the number one cause of serious adult disability in the United States. Nearly three-quarters of all strokes occur in people over age 65, and the risk of having a stroke more than doubles with each decade of life after age 55 (CDC, National Center for Health Statistics, Stroke, www.CDC.gov).

In 2005, among people over 50, about 457,000 had stroke as a primary diagnosis, and, of these people, about 90 percent were recent strokes (within the last year; AHRQ, 2005). Among Medicare beneficiaries over 65 in the traditional program, the prevalence of stroke was more than 5 percent in 2006, of which almost 60 percent were recent (within the last year). The declining proportion of recent strokes suggests that survival rates are improving, allowing more people who have had a stroke to live longer. Extended survival also means that older stroke patients continue to require treatment for longer periods.

More than 65 percent of people over 50 with stroke have four or more other chronic conditions and many also have functional impairments. Among people over 50 with stroke, about 37 percent have impairments in three or more daily activities. Among Medicare beneficiaries over 65, more than 82 percent had five or more chronic conditions (including stroke) in 2006 and, of these people, about 18 percent died. Stroke is often associated with other chronic conditions, such as hypertension (70 percent), diabetes (22 percent), and heart disease (37 percent). Medicare beneficiaries over 65 who have had a stroke experience above-average prevalence of other chronic conditions, with double the rates of atherosclerosis and congestive heart failure.

Strokes frequently recur, with about 25 percent of stroke patients experiencing another stroke (National Institute of Neurological Disorders and Stroke, www.ninds.nih.gov). As a result, people with stroke have frequent encounters with the health care system (Table 2 on page 21). Among Medicare beneficiaries over 65 in the traditional program, the average program cost per stroke patient (primary diagnosis) was more than \$21,000, which accounted for Medicare spending of about \$31 billion in 2006.

Stroke is a condition that is suitable for care coordination in all phases (prevention, acute care, rehabilitation, and chronic care) because it is a relatively common condition with serious clinical outcomes and variable practice patterns, and often incurs high cost for care. Core components of an effective stroke program include patient education, risk factor screening, primary care, stroke specialty units, rehab services, home care, community services, support for caregivers, and care coordination (Venketabrusamarian et al., 2002).

Care coordination provided for three months to recovering stroke patients can increase adherence to self-care practices (which patients can do themselves to help their recovery), reduce depression, and improve quality of life (Claiborne, 2006). A comprehensive care coordination program that includes home telehealth could aid stroke patients and their caregivers in managing recovery across the continuum of care at home and in the community (Lutz, Chumbler, & Roland, 2007). During the first three months following a serious disabling stroke, specialized (inpatient) stroke units produced better patient outcomes after one year (e.g., lower mortality and greater functional improvement) than routine inpatient care or home care and, depending on the payment system, could be more cost effective (Kalra et al., 2005).

Family caregivers of stroke patients need support for their role (Lane, McKenna, Ryhan, & Fleming, 2003). However, caregivers encounter important barriers to undertaking and maintaining their caregiver role, such as lack of collaboration from the health care team and lack of community support. Factors that support the caregiver role include coordination of care, a supportive social environment, and mastery of the caregiving role (White et al., 2007).

CANCER

Cancer, in many forms, has become a serious chronic condition. While the term *cancer* was once commonly equated with “terminal,” five-year survival rates, which oncologists often refer to as a “cure,” exceed 80 percent for many forms of cancer. This means that increasing numbers of people, particularly those over 50, are living with cancer for years. On the other hand, cancer can and does lead to serious complications and death, and collectively it represents one of the most common causes of death in the United States. In 2005, the prevalence of all forms of cancer was more than 6 percent among people over 50 (AHRQ, 2005). Among Medicare beneficiaries over 65 in the traditional program, the prevalence of cancer was about 15 percent in 2006, up from about 12 percent in 1997, in part because more people are living longer with it (CMS, 1997 and 2006).

About 30 percent of people over 50 with cancer have four or more additional chronic conditions, and about 26 percent have impairments in three or more daily activities (AHRQ, 2005). Among Medicare beneficiaries over 65 in the traditional program, about 55 percent had four or more other chronic conditions in 2006 and, of these people, about 12 percent died.

People with cancer have frequent encounters with the health care system. For instance, in 2006, traditional Medicare beneficiaries over 65 had almost 29 doctor visits per capita, almost 36 percent of cancer patients had ER visits, and about 34 percent were hospitalized for an average of about 3.8 days (CMS, 2006). Along with higher health care utilization came higher rates of potentially avoidable encounters, such as hospital readmission (27 percent within 30 days of discharge) and post-discharge ER visits (24 percent within 30 days of discharge).¹¹

Among traditional Medicare beneficiaries over 65, the average program cost per cancer patient (primary diagnosis) was more than \$14,000, which accounted for total Medicare spending of almost \$57 billion in 2006.

Although many cancers can often be treated on an outpatient basis, many cancer patients are still hospitalized. Cancer care is poorly coordinated during and after treatment (Ganz, Casillas, & Hahn, 2008). A recurring theme is that patients lack coordination of care and their needs are not being adequately met (Moyez et al., 2008). Obstacles that interfere with delivery of high-quality cancer care include lack of standardized or adherence to

clinical guidelines, insufficient teamwork among multidisciplinary care teams, lack of patient awareness and empowerment, diagnostic delays during provider transitions, and excessive reimbursement for treatment (Aiello Bowles et al., 2008).

Various approaches to cancer care coordination have been tested and appear to improve care on a number of measurement parameters. Implementation of common assessment tools, collaborative care plans, and symptom management guidelines have reduced ER visits and hospital admission for cancer patients by improving care coordination, quality, and integration of palliative care without increasing the intensity of patient symptoms or caregiver burden (Dudgeon et al., 2008). Among cancer patients undergoing chemotherapy, care coordination and telehealth technologies to manage symptoms like emotional distress and pain have reduced unnecessary use of inpatient and outpatient services (Chumbler et al., 2007). Nurse coordinators can improve the quality of care for head and neck cancer patients undergoing a complex treatment regimen by bridging communication gaps between patients and providers and improving care coordination (Wiederholt et al., 2007). Informal caregivers of cancer patients would benefit from structured assessment of their needs related to arranging and coordinating services and increasing their competence as caregivers (Osse et al., 2006).

ENDNOTES

- ¹ The Medical Expenditure Panel Survey Household Component, cosponsored by the Agency for Healthcare Research and Quality (AHRQ) and the National Center for Health Statistics (NCHS), is a nationally representative longitudinal survey that collects detailed information on health care utilization, health insurance, health status, and other social demographic and economic characteristics for the civilian non-institutionalized population in the United States. Clinical conditions were based on physician diagnosed conditions reported by respondents. Clinical conditions were aggregated into clinically meaningful categories using the Clinical Classification System (CCS) developed by AHRQ. Medical conditions were further defined as chronic or non-chronic based on subsets of CCS codes for chronic conditions developed by Wenke Hwang (see Hwang, 2001.) Gerard Anderson, professor of health policy at the Bloomberg School of Public Health and professor of medicine at Johns Hopkins University, supervised the data analysis and worked with analysts at AARP to ensure that data were statistically accurate and reflected the current literature in the field.
- ² Medicare data for calendar year 1997 and 2006 were derived from a 5 percent sample of patients aged 65 and older who were enrolled in both Parts A and B of the fee-for-service program. Disabled beneficiaries and those enrolled in Medicare Advantage are not included. Costs also exclude Part D, ESRD, and cost-sharing amounts. Clinical conditions were based on International Classification of Disease Version 9 (ICD-9) codes as filed on Medicare claims. Like the MEPS, clinical conditions identified from Medicare claims were aggregated into clinically meaningful categories using AHRQ's CCS and were defined as chronic or non-chronic based on CCS codes developed by Hwang.
- ³ Excluding dementia and senility.
- ⁴ Statins are drugs that are used to lower cholesterol. They work by blocking a substance the body needs to make cholesterol.
- ⁵ Chronic obstructive pulmonary disease (COPD) is the overall term for a group of chronic lung conditions that obstruct the airways in the lungs. COPD usually refers to obstruction caused by chronic bronchitis and emphysema, but it can also refer to damage caused by asthmatic bronchitis.
- ⁶ Diabetic retinopathy is a complication of diabetes that results from damage to the blood vessels of the light-sensitive tissue at the back of the eye (retina).
- ⁷ Expenditures in MEPS are defined as the sum of direct payments for care provided during the year, including out-of-pocket payments and payments by private insurance, Medicare, Medicaid, and other sources. Payments for over-the-counter drugs and indirect payments not related to specific medical events such as Medicaid Disproportionate Share and Medicare Direct Education subsidies are not included.
- ⁸ The 10 highest-cost health conditions in 2005 were heart disease, trauma, cancer, mental disorders, pulmonary conditions, hypertension, diabetes, osteoarthritis, back problems, and kidney disease (AHRQ, 2005).
- ⁹ Costs include Medicare payments under Parts A and B of the fee-for-service program. Costs for disabled beneficiaries and those enrolled in Medicare Advantage are not included. Costs also exclude Part D, ESRD, and cost-sharing amounts.

¹⁰ Osteoarthritis, a degenerative joint disease, is the most common form of arthritis and occurs as cartilage in the joints wears down over time. It occurs most often in older adults. Rheumatoid arthritis is

an inflammatory, autoimmune disorder that causes joint pain and damage and may also affect other organs. It often occurs in women between the ages of 40 and 60 but can occur at any age.

¹¹ Data reflect all hospital readmissions and emergency room visits within 30 days of discharge.

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2

The Many Faces of Chronic Disease

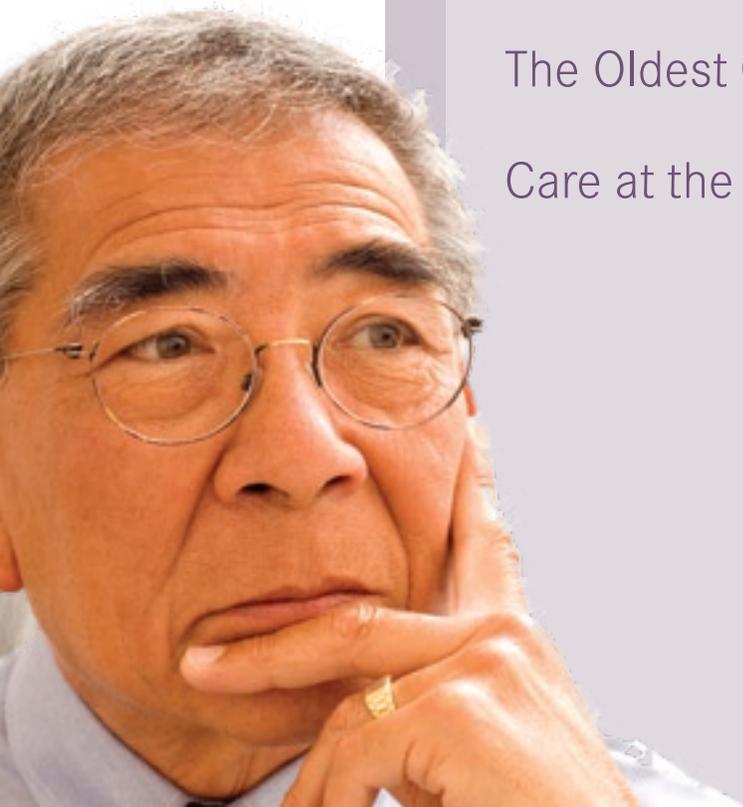
Trajectories

Patient and Informal Caregiver
Experiences

Special Challenges Associated with
Poor Access to Care

The Oldest Old

Care at the End of Life



The experience of chronic disease varies widely. At one end of the spectrum are people with mild chronic diseases who are in other respects healthy and do not have functional limitations. At the other end of the spectrum are people with multiple chronic conditions and severe functional limitations, who are more likely to be among the “oldest old” (ages 85 or older). As we discussed in Chapter 1, over time, many of the healthier people with chronic illness will develop new or more serious conditions and disabilities.

“They don’t assist on the transition home. You have to be tough, be an advocate....I’d like somebody to tell me what’s available. I don’t know.” [“David” is an 82-year-old Richmond caregiver caring for his wife, 64, who has terminal cancer and dementia.]

For the healthiest group of people with chronic disease, improving care might mean focusing on great patient education and involvement so that the individual takes charge of his or her own illness. This could involve healthy behaviors like stopping smoking, eating a healthier diet, and reminders to adhere to medication therapies.

For the people with the most severe or multiple conditions, and those with functional limitations, the focus of improving care will be different. Medication adherence and healthy behaviors are still important, but

for many this will not be enough. These people are more likely to go to hospitals, emergency rooms (ERs), and long-term care facilities and thus be more susceptible to “falling through the cracks” as they transition among settings. They are more likely to need supportive services to help them with activities of daily living or arrange for transportation, and they are more likely to rely on an informal caregiver, such as a spouse, relative, or friend.

Providing high-quality, coordinated care for people with chronic illnesses can be a challenge. However, providing care for chronically ill patients with barriers to health care, such as people who do not have insurance and people who do not speak the same language as their providers, is even more of a challenge.

This chapter describes the experiences of people with chronic disease. We describe the trajectory of care that people often face as their conditions worsen over time. We also provide a multifaceted portrait of people’s experiences through patients’ and caregivers’ own words, describe the challenges for people with barriers to access, and provide a focus on care for the oldest old and those at the end of life.

TRAJECTORIES

The course of illness, or “trajectory,” of people with chronic conditions can be quite varied and is likely to depend on many factors, such as the type and severity of illness, the presence of other co-morbid conditions, response to therapies, and functional limitations. Of course, non-clinical factors such as genetics, environmental influences, and social support also play an important role.

Understanding the course of illness can be helpful in developing a plan of care, managing and coordinating health and supportive services, avoiding unnecessary and inappropriate care, providing appropriate education and support for patients and caregivers, and reducing anxiety and addressing concerns.

Trajectories for people with chronic conditions may be characterized along a number of dimensions, such as severity of illness, life expectancy, quality of life, functional ability, and patterns of health care utilization or cost.

Researchers have begun to identify a number of discrete paths or “trajectories” that most people follow. During initial onset, symptoms of many chronic conditions, such as hypertension, high cholesterol, and osteoporosis, may remain minor or essentially silent for years, especially once

the condition is diagnosed and under treatment.

As chronic conditions progress, symptoms may vary and may not follow an inevitable course of increasing severity. Some conditions, such as coronary artery disease, severe arthritis, and kidney failure, may improve dramatically with treatments such as joint replacement, coronary artery bypass graft (CABG) surgery, or organ transplant. Certain conditions may lead to gradual decline and frailty (e.g., Alzheimer’s and Parkinson’s diseases), while others may follow a rapid, inexorable decline (e.g., many cancers) or result in sudden death without prior warning (e.g., heart attack).

The link between chronic conditions and disability is well established, with chronic disease being the main contributor to disability (Wolff, Boult, Boyd, & Anderson, 2005). Research suggests that when people have multiple chronic conditions, the course of their illness tends to worsen along a number of parameters, including health status, functional ability, and life expectancy, as well as increase health care utilization and cost of care (Wolff, Starfield, & Anderson, 2002; Wolff, Boult, Boyd, & Anderson, 2005).

The progression of chronic illness, particularly when combined with

AARP conducted six focus groups in December 2007. Three groups with chronically ill people over age 50 included a total of 19 who had experienced a transition from a hospital or other health care facility in the last two years. Three groups included a total of 17 caregivers of chronically ill people over age 50 who had experienced a transition from a hospital or other health care facility in the last two years. Four focus groups were conducted in Philadelphia. Two of these groups consisted of patients and caregivers who had received a care coordinator as part of a research program sponsored by a prominent school of nursing in Philadelphia. The remaining two Philadelphia groups and two groups conducted in Richmond did not have access to a care coordinator. The school of nursing and a focus group research firm under contract to AARP recruited the four Philadelphia groups with permission from an Institutional Review Board (IRB), while the Richmond participants were recruited and screened by the focus group research firm, which also provided a facilitator for all six focus groups.

the addition of new chronic conditions, increases the need for health care and support services as well as care coordination. Patients must not only learn to manage their condition(s) medically but also adapt to life with some level of functional dependency (Wolff, Boulton, Boyd, & Anderson, 2005).

People with serious chronic illnesses, such as congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD), experience rapid changes in severity of illness and health care needs. Opportunities for people with these conditions have been identified for improved care through programs that include patient education, symptom monitoring, and reducing hospitalizations. In addition, these individuals may benefit from more intensive advance care planning services that educate them about hospice care and help them better understand scenarios in which “extreme measures” may become futile (Lunney, Lynn, & Hogan, 2002; Lunney et al., 2003).

While some researchers have described patient trajectories in terms of changes in functional ability, others have found little relationship between functional limitations and life expectancy, with nearly half of people dying without reporting any functional limitation (Rudberg et al., 1996). On the other hand, researchers have found that the burden of chronic illness rises with age (Lunney, Lynn, & Hogan, 2002).

PATIENT AND INFORMAL CAREGIVER EXPERIENCES

From the perspective of patients with chronic conditions and their caregivers, the health care system can be a daunting place. As shown in Chapter 1, these people have frequent contacts with many different health professionals and providers, and often experience many transitions across care settings.

These myriad interactions, particularly those involving transitions, increase opportunities for mishaps and problems to arise. These risks can be magnified as patients are weakened by multiple chronic illnesses, become frailer, and experience sensory and cognitive impairments, such as hearing loss, decreased vision, and failing memory. As the burden of chronic illness increases for people, so the demands tend to increase on caregivers, many of whom may also be challenged by their own illness.

Many of these problems contribute to patients and caregivers’ “falling through the cracks” in our health care system, resulting in lapses or inappropriate care. Lapses in care can arise for reasons that relate to both

providers and patients. These lapses often result from poor or incomplete communication and/or understanding. As described further below, findings from focus groups conducted by AARP are consistent with, among other things, a study that found that many patients do not understand the care they received or what they should do after discharge from a health care facility. Moreover, most people appear unaware of their lack of understanding and report inappropriate confidence in their comprehension and recall (Engel et al., 2008). While this study was limited to people with emergency department visits, our focus groups suggest that these problems may be typical of transitions across other health care settings.

Sometimes a lack of communication and information sharing among providers may result in too little or too much care, such as missed appointments, receiving duplicate medical tests, and low satisfaction among patients, caregivers, and providers. Communication difficulties, such as conflicting advice from providers or failure to arrange follow-up care, may result in more serious problems, such as avoidable complications, emergency visits, and hospital admissions. Because of the volume and complexity of new information and the often-compromised mental status of

patients, the risk of falling through the cracks is increased for people with newly diagnosed conditions and for those who have been recently discharged from a hospital or other facility.

To find out where and how they might be falling through the cracks, we asked individuals with chronic conditions and caregivers to describe some of the problems they have encountered receiving care. We conducted focus groups, including caregivers and individuals over age 50 with chronic conditions who had experienced at least one transition.

TRANSITION ISSUES

People with chronic conditions and their caregivers expressed many concerns about transitions from hospitals and other health care facilities. Overall, transitions were stressful and created many communication and other issues.

The most frequently mentioned issues were:

- Loss of mobility and/or independence
- Uncertain expectations for recovery and/or prognosis
- Pain
- Anxiety
- Not remembering their doctor's instructions
- Feeling abandoned

The most frequently mentioned issues for caregivers were:

- Finding resources, such as medical equipment and services
- Arranging for assistance in and around the home, both paid and unpaid
- Communicating with doctors and other health professionals
- Finances/affordability
- Uncertain expectations for their relative's or friend's recovery and/or prognosis
- Managing their relative's or friend's expectations
- Not enough time for competing demands (e.g., care coordination, job, children, self)
- Stress/emotional strain/guilt

Patients and caregivers both told stories of falling through the cracks.¹

Many individuals and caregivers felt that the “ball was dropped” after discharge. Several mentioned that the hospital discharge planner or social worker helped them before discharge, but once they left the hospital they were on their own.

- “If you don't get it while you're in there, when you go home, you're out of luck.” [*Mary, a 74-year-old Philadelphia patient with congestive heart failure, hypertension, coronary artery disease, stomach surgery, spinal fusion, and chronic pain, had*

been admitted to the emergency room once, hospitalized once, underwent rehabilitation therapy for two years, and lives with her daughter.]

- “Following you home, that never occurred and, you know, a whole lot can happen between leaving the hospital and getting home.” [*Louis, a 77-year-old Philadelphia patient with congestive heart failure, coronary artery disease, arthritis, gout, memory loss, chronic pain, and using a walker, had been admitted to the emergency room three times, hospitalized three times, admitted to a skilled nursing facility three times, and lives with his frail wife, who is 76 years old and also has memory loss.*]
- “They would discharge me and the same day I’d be back in the ER [emergency room]. The wound would dehisce [burst apart].” [*Michael, a 71-year-old Philadelphia patient with a knee replacement requiring two surgical revisions, diabetes, draining foot ulcer for 12 months, carrying a vacuum drain, and using a walker, had been admitted to the emergency room once, hospitalized four times, and lives with his 73-year-old wife.*]
- “I was afraid I would fall down again or faint. I looked into an alert system but couldn’t afford it. I called Elder Health [a community support organization] but they couldn’t help.” [*Ruth, an 81-year-old Philadelphia patient with hypertension, stroke, atrial fibrillation, pacemaker, coronary artery disease, and glaucoma, had been hospitalized once, received home health services, and lives alone.*]

Many patients, especially those newly diagnosed or discharged from a health care facility for the first time, and caregivers did not know what to expect, where to find resources, or what services they would need, either in terms of health care or support services.

- “They don’t assist on the transition home. You have to be tough, be an advocate....I’d like somebody to tell me what’s available. I don’t know.” [*David is an 82-year-old Richmond caregiver caring for his wife, 64, who has terminal cancer and dementia.*]
- One caregiver said the hospital did not explain that home health care was available or that Medicaid would cover it. Another caregiver said no one told him that liquid oxygen was more convenient than oxygen in canisters, so for months he had struggled needlessly with heavy, bulky oxygen tanks.
- “Finding resources is still a big problem. They call back months later and they don’t know the answer to the question.” [*Joanne is a 79-year-old Philadelphia caregiver caring for her 84-year-old husband with coronary artery disease, angina, angioplasty, back pain, walking problems, hearing problems, and many transitions.*]
- “Before a person leaves the hospital, the caregiver must see somebody who just explains, ‘You will feel guilty, you will feel frustrated, you will feel overwhelmed. If you feel that, it’s a normal reaction.’” [*Joanne is a 79-year-old Philadelphia caregiver.*] “It would be nice if the caregivers could get this kind of thing individually, not while the patient is sitting there.” [*Bernice is a 73-year-old Philadelphia caregiver.*]
- “There was no help at home [after surgery]. My mother came and took care of household stuff. I was flat on my back for two weeks. The hospital called to make sure I was doing okay—‘Hey, how are you doing?’—but what could they do?” [*Bill, a 50-year-old Richmond patient with heart attack, open heart surgery (CABG), angioplasty with stent placement, stroke, kidney disease, HIV, and depression, had been hospitalized three times, underwent rehabilitation therapy in an inpatient facility once, and lives alone.*]

Many patients had difficulty with discharge instructions.

- “By the time I’m home, I don’t remember what the doctor said. Sometimes they write it down, but I have comprehension problems.” [*Bill is a 50-year-old Richmond patient.*]
- “A lot of times, people are intimidated by doctors and staff.” [*Michael is a 71-year-old Philadelphia patient.*] “A lot of times, we don’t know what we need or we don’t ask, ‘Hey, what’s this pill for?’” [*Robert, an 84-year-old Philadelphia patient with coronary artery disease, angina, angioplasty with stent placement, back pain, walking problems, and hearing problems, had been admitted to the emergency room twice, hospitalized three times, underwent rehabilitation therapy once, and lives with his 79-year-old wife.*] “A lot of things I think I can handle myself but we [patients and caregivers] are not medical people and we don’t know the terminology that they use, the doctors’ language. The doctor talks about ‘edema,’ I talk about ‘swelling.” [*Michael is a 71-year-old Philadelphia patient.*]

Sometimes they may not know when they have fallen through a crack in the system.

- “We don’t know what we don’t know.” [*Joanne is a 79-year-old Philadelphia caregiver.*]
- “My social worker was very good with things that I asked her about. It might have taken a little while to find out but when I was waiting to get an answer, every time I’d see her, I’d wave her down and she’d say, ‘I haven’t forgotten about you.’” [*Louis is a 77-year-old Philadelphia patient who apparently thought he was receiving attention while he was actually kept waiting over repeated visits.*]

IMPACT OF CHRONIC CONDITIONS

Patients reported chronic conditions affect lifestyle and activities.

- “It keeps me from doing things I’d like to do because I can’t breathe.” [*Ann, a 65-year-old Richmond patient with COPD, pneumonia, and diabetes, had been admitted to the emergency room once, hospitalized once, and lives with her mother.*]
- “I was more active going out to the movies and things like that [before getting sick].” [*Anonymous Philadelphia patient.*]

About two-thirds of study participants either received or provided assistance with activities of daily living and chores, such as housekeeping, errands, groceries, and pharmacy. About 40 percent received paid assistance from a home health agency or visiting nurse agency.

- “I have someone to help with errands and stuff around the house two hours a day.” [*Anonymous Philadelphia patient.*]
- “We have a nurse three days a week, two hours a day. That’s a big help. My mom is physically sick but her mind is great except she forgets her medications sometimes.” [*Beverly is a 49-year-old Philadelphia caregiver caring for her 74-year-old mother with stomach surgery, spinal fusion, chronic pain, congestive heart failure, hypertension, coronary artery disease, and multiple transitions (emergency room visits, hospitalizations, rehab therapy, and nursing home admissions).*]

Some patients believe they can manage effectively with their condition(s).

- “I’m 88 and I think I do quite well. I do everything myself except cleaning and the groceries.” [*Doris, an 88-year-old Philadelphia patient with hip replacement, knee replacement, and hypertension, had been hospitalized three times, uses home health agency services, and lives alone.*]

Caregivers report significant stress, altered living arrangements, reduced working hours, and need for emotional support.

- “As caregivers, emotionally and mentally, sometimes we’re just not at our top, we’re not working at our best level.” [*Bernice is a 73-year-old Philadelphia caregiver.*]
- “I used to have help, but my mom needs diapers, and I can’t turn her over, and we have to feed her, so we can’t get help [apparently due to the complexity and frequency of care required]....It’s overwhelming. My blood pressure is over 200 and I had blood in my eyes. It is a lot of stress.” [*Jim is a 48-year-old Philadelphia caregiver caring for his 77-year-old mother with stroke, diabetes, rheumatoid arthritis, and multiple transitions (emergency room twice, hospitalized twice, admitted to a nursing home once, and underwent rehab therapy once).*]
- “I moved so everything is on the first floor for my mom.” [*Beverly is a 49-year-old Philadelphia caregiver.*]
- “It is impacting me financially. I had to quit my job. I hate to leave her alone.” [*Wendy is a 38-year-old Richmond caregiver caring for her 84-year-old mother with stroke, pneumonia, feeding tube, and dementia, who wanders.*]

ARRANGING FOR CARE

Many patients or their family caregivers spend a lot of time arranging for their care.

- “Sometimes, I have to spend all day on the phone to my doctor, even to get an appointment.” [*Ruth is an 81-year-old Philadelphia patient.*]

Most patients and caregivers do not want to give up control over their care.

- Patients and caregivers want advice and support from a trusted source. Many patients and caregivers do not trust insurers or providers to act in the best interest of patients. They fear insurers are out to save money. In the following example, one caregiver thought the hospital had recommended transferring his mother to a nursing home, just to get rid of her. “I can’t trust the facility that my mother was in because of me not coordinating and not watching and I feel responsible.... For example, my mother had been in this facility for three days. You mean to tell me there wasn’t a list of her medications that didn’t follow her from the hospital? So now she’s back in the hospital, the same hospital she just left, so now they’re getting to make some more money.” [*Jim is a 48-year-old Philadelphia caregiver.*]
- “You can’t trust the doctors because they’re all in cahoots.” [*Mary is a 74-year-old Philadelphia patient.*]

Caregivers want their own advice to the patient reinforced, not undermined.

- “Sometimes it’s hard for the person [the caregiver] that is directly involved with the patient, you know, they [patients] don’t pay attention to us [caregivers], especially if it’s a parent, or they [patients] don’t take direction too well from us [caregivers].” [*Bernice is a 73-year-old Philadelphia caregiver.*]

Some caregivers thought that patients (their relative or friend) lack incentives to comply with a doctor's recommendations.

- “If it's something that they [patients] really need, why is it [doctor's advice] a suggestion?...You really need somebody to tell it like it is sometimes.” [*Bernice is a 73-year-old Philadelphia caregiver.*]
- “The patient is, many times, suffering from some kind of chronic illness or mental problem which can affect how you feel about things.” [*Bernice is a 73-year-old Philadelphia caregiver.*]
- “It would benefit an insurance company a zillionfold if somebody were helping you transition because...when you and the patient come out [of the hospital], here you are, two dummies, one sick and one dummy. What do you do? Where do you go? You make a million phone calls. You do a lot of things that are stupid and nothing gets done.” [*Joanne is a 79-year-old Philadelphia caregiver.*]

Patients often need someone to accompany them to office visits to help them clarify their problems, remember provider recommendations, and comply with recommended therapies and follow-up care.

- “My mother's not in a condition to do nothing, to start nothing, or stop nothing; she not in that condition to do nothing.” [*Angela is a 60-year-old Philadelphia caregiver caring for her 85-year-old mother with arthritis, dementia, vertigo, and multiple transitions (emergency room visit once, hospitalized once).*]

Almost 39 percent of Medicare beneficiaries bring medical visit companions to routine office visits, and those who do are more satisfied with care (Wolff & Roter, 2008).

Our focus groups taught us some other important lessons about patients with chronic conditions and their caregivers, although participants did not always state the issues explicitly.

- Patients and caregivers like personal contact, not just telephone calls.
- Patients and caregivers like continuity of care, not frequently changing personnel.
- Younger patients seem better able to manage and coordinate their own care, even when apparently sicker based on medical indicators, than older, frailer patients.
- Patients most in need of assistance are often those without caregivers.
- The ability to self-manage care depends to some extent on availability of public and community support services, such as homemaker services, meals-on-wheels, shopping, prescription pick-up, and community adult day care.
- Many patients and caregivers acknowledged that, with enough time and experience, things started to fall into place.
- Patients on Medicaid often seemed to have better support than non-Medicaid patients with low income.

SPECIAL CHALLENGES ASSOCIATED WITH POOR ACCESS TO CARE

In this section, we focus on two special challenges associated with poor access to care. The first is the challenge experienced by older adults who speak languages that differ from that of their provider. The second relates to the problems faced by older adults with chronic illnesses who lack access to health insurance.

According to the American Community Survey, in 2006, 13.9 percent of Americans ages 65 and older spoke a language other than English at home, and a sizable share of those older Americans (5.3 percent) reported having limited English proficiency.

These numbers are up from 12.3 percent and 4.0 percent, respectively, just six years ago, and are expected to grow as the number of minority Medicare beneficiaries increases (AARP Public Policy Institute analysis of American Community Survey, 2006).

WHAT IS LIMITED ENGLISH PROFICIENCY?

Effective management of chronic illness heavily depends on the ability of patients and their providers to communicate with one another (Piette et al., 2003). Language barriers between patients and their providers can result in substandard care and medical errors (Institute of Medicine [IOM], 2003). Communication barriers exist in many forms; this section focuses on the barriers that can arise when providers and patients speak different languages. People who do not speak English as their primary language or whose ability to read, write, speak, or understand English is limited are defined as limited English proficient (LEP; U.S. Department of Health and Human Services, 2003).

IMPACT OF LIMITED ENGLISH PROFICIENCY ON HEALTH CARE AND HEALTH OUTCOMES

Older adults who are eligible for Medicare and who have limited or no English proficiency face significant challenges as they seek to navigate the complexities of the U.S. health care system (IOM, 2003). LEP Medicare beneficiaries may not fully understand how the program works and, therefore, may not access the benefits to which they are entitled (Jost, 2005). Those who do manage to access Medicare-covered services may find that their LEP status makes them unable to communicate effectively with their providers and other health professionals (Jost, 2005). The problems may be compounded for LEP patients who have chronic illnesses. A 2006 study found that LEP Medicare beneficiaries had less access to a usual source of health care and to preventive cancer screenings than beneficiaries who were not LEP (Ku, 2006). Other studies have found the following:

- People who face language barriers are less likely than others to have a usual source of medical care, are less likely to receive preventive services, and may be less likely to adhere to medication instructions (Flores, 2006).
- When Spanish-speaking people are discharged from ERs, they are less likely to understand their diagnosis or follow-up instructions, including how to properly take their medications (Jost, 2005).
- When Spanish-speaking patients have doctors who do not speak their language, they are more likely to not take their medications as instructed, miss their scheduled doctor appointments, and use ERs for care than those with Spanish-speaking physicians (Jost, 2005).
- When people whose primary language is Spanish were seen by Spanish-speaking physicians, they asked more questions and had a

better understanding of their conditions than when they saw physicians who did not speak Spanish (Ngo-Metzger, 2007).

- LEP individuals who had physicians who did not speak their language had more problems understanding medication instructions and more medication-related problems (Ngo-Metzger, 2007).
- Chinese and Vietnamese LEP individuals whose providers did not speak their languages were less likely to receive health education services compared with those whose providers spoke their languages. They were also less satisfied with their care and experienced worse interpersonal relationships with their providers (Ngo-Metzger, 2007).
- People with diabetes and hypertension reported better health outcomes when their physicians spoke their native language (Ngo-Metzger, 2007).

Language barriers make it hard for people who have no or limited English skills to effectively participate in their own health care. The problem can be especially acute for LEP Medicare beneficiaries experiencing one or more chronic illnesses. Examples of problems that can arise when patients and providers are unable

to communicate effectively include the following:

- Inability of providers to obtain accurate medical histories and to elicit patient's concerns (IOM, 2003)
- Increased use of medical tests and procedures (IOM, 2003)
- Inability of people to understand consent forms (IOM, 2003)
- Increased possibility of medical errors (IOM, 2003)
- Poor patient compliance with treatment plans (IOM, 2003)
- Poorer patient outcomes (Perkins, Youdelman, and Wong, 2003)

THE CHALLENGES OF BEING UNINSURED

People who have health insurance are more likely to have a regular source of health care and clinical preventive services (Xu, 2002). In addition, among people with multiple chronic conditions, those who also have health insurance are more likely to experience improved continuity of care that may ultimately improve their health outcomes (IOM, 2002).

Older adults with chronic illnesses who do not have health insurance are less likely to receive routine preventive services, ongoing care for their chronic conditions, or help coordinating multiple providers

and the variety of prescription drugs they are frequently required to take. A recent study found that millions of uninsured Americans with chronic diseases, such as diabetes or high blood pressure, do not receive adequate treatment for their conditions. The study estimated that because they do not have the financial access to health care that insurance provides, about one in three uninsured working-age adults in the United States never receive the care necessary to effectively manage their chronic conditions (Wilper et al., 2008).

Once they reach age 65, the majority of older adults are eligible for Medicare Part A (the hospital insurance part of Medicare). According to one study, those who were uninsured during the years leading up to Medicare eligibility often came into the program in worse health and used more health services than those who were insured prior to Medicare eligibility (McWilliams, Meara, Zaslavsky, and Ayanian, 2007). Health insurance coverage has the potential to significantly improve access to appropriate care for a range of preventive, chronic, and acute care services. Other benefits associated with health insurance coverage among the pre-Medicare population include improved health status, increased productivity, and potentially lower future Medicare spending.

Access to care is worse for older adults who are uninsured.

Those older adults (ages 55 to 64) who are without health insurance have worse access to care than their counterparts who have access to private or public health insurance coverage. After controlling for a variety of variables, a 2004 study by Holahan found statistically significant relationships between lack of health insurance and the absence of a usual source of care among the near-elderly group (Figure 2.1; Holahan, 2004; Dorn, 2008). It is important for adults who have one or more chronic diseases to have regular visits with their health care providers in order for their conditions to be managed well. Yet, the 2004 study reported that “only 59 percent of the uninsured older adults had a physician visit in the past year compared with 88 percent of those with private coverage and 84 percent of those with public coverage” (Holahan, 2004).

Uninsured older adults are less likely to get the care they need.

Uninsured older adults who do not have health insurance coverage are also more likely than their insured counterparts to go without the care they need (Figure 2.2; Holahan, 2004; Dorn, 2008). Compared with their insured counterparts, near-elderly adults who are uninsured often receive less preventive care (Hadley, 2002) and go without

needed medical and surgical care, prescription drugs, and dental care (Holahan, 2004; Dorn, 2008). Among the near-elderly uninsured, 10 percent are more likely to go without needed medical or surgical care; 8 percent do not access the prescription medicines they need to manage their health conditions; and 16 percent do not receive needed dental care (Figure 2.2; Holahan, 2004).

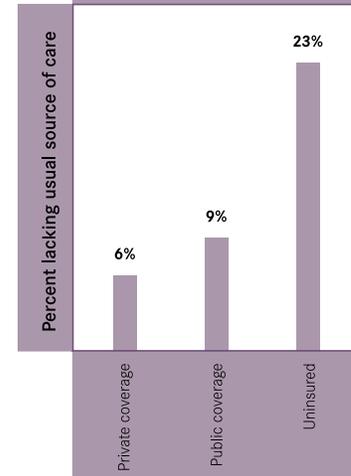
The burden of chronic disease is higher among the uninsured.

The uninsured tend to have their illnesses diagnosed at more advanced stages, receive fewer pharmaceutical and surgical treatments, and, for certain chronic illnesses, have worse clinical outcomes than their insured counterparts (IOM, 2002; Hadley, 2002). Although the Institute of Medicine reported that three chronic conditions—diabetes, cardiovascular disease, and renal failure—respond well to evidence-based primary care and treatment (IOM, 2002), those who are uninsured are not likely to access this important care and are more likely to receive the care of last resort—emergency room and acute hospital care (IOM, 2002).

Diabetes

Uninsured adults with diabetes are less likely to have their blood sugar levels monitored consistently, which is a recommended standard

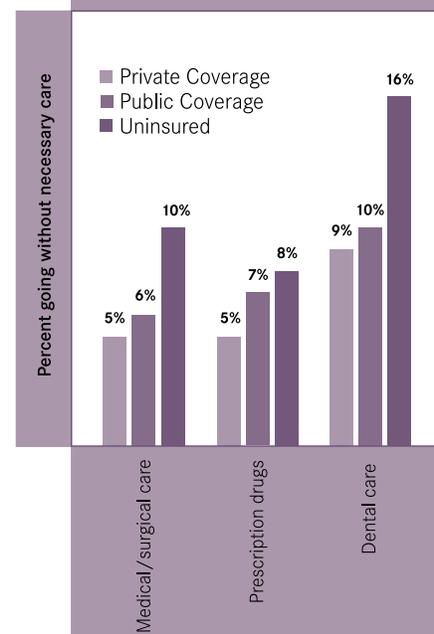
Figure 2.1:
Uninsured Adults More Likely to Lack a Usual Source of Care



Source: Holahan, 2004. Calculations by S. Dorn, 2008.

Note: Data reflect adults ages 55 to 64 in 2002.

Figure 2.2:
Uninsured Adults More Likely to Go without Necessary Care



Source: Holahan, 2004.

Note: Data reflect adults ages 55 to 64 in 2002.

of care for diabetics (IOM, 2002). Diabetics with uncontrolled blood sugar levels are at increased risk for diabetes-related hospitalizations and other complications of the disease, such as high blood pressure, kidney failure, and disability (e.g., amputations and blindness). A report published by the Institute of Medicine found that one-quarter of diabetics who have been uninsured for a year or more go without a checkup for two years (IOM, 2002). Thus, lack of health insurance places diabetics at significant risk for bad health outcomes associated with the diagnosis.

Cardiovascular Disease

Uninsured adults who are diagnosed with cardiovascular diseases are less likely to have adequate access to the health care they need. They are therefore also less likely than those with insurance to receive ongoing monitoring of two key indicators of heart disease—blood pressure and blood cholesterol levels. They are also less likely to be able to afford medications that can potentially improve or stabilize their conditions, and are at greater risk for experiencing complications of heart disease, such as heart attack or stroke, than their insured counterparts (IOM, 2002). According to a report issued by the Institute of Medicine, studies show that the uninsured represent

a disproportionate number of people admitted to ERs with severe uncontrolled hypertension (IOM, 2002). The report cited a study that found that among uninsured adults, 19 percent of those diagnosed with heart disease and 13 percent diagnosed with high blood pressure did not have a usual source of receiving health care, compared to 8 and 4 percent, respectively, of their insured counterparts (IOM, 2002).

End-Stage Renal Disease (ESRD)

Research suggests that detecting chronic kidney disease early and initiating appropriate medical care can delay or even prevent the disease from progressing to permanent kidney failure (The Medicare Payment Advisory Commission [MedPAC], 2004). Those who are at high risk for the disease (e.g., people with diabetes, older people, people with hypertension, and minorities) are likely to gain the most benefit from early interventions (MedPAC, 2004). There is significant research support for the conclusion that early referral to kidney specialists plays an important role in reducing ESRD-related complications (MedPAC, 2004).

Almost all people with ESRD qualify for Medicare once they need dialysis (a process by which wastes and excess fluids are removed from the body) or a

kidney transplant (MedPAC, 2004; IOM, 2002). However, people who were uninsured before becoming eligible to receive Medicare-financed dialysis treatment were in poorer health than their insured counterparts, and they experienced more negative effects from dialysis on their overall health status and feeling of well-being (IOM, 2002).

THE OLDEST OLD

In this section, we refer to the oldest old as those who are ages 85 years and older; the middle old as those between ages 75 and 84; and youngest old as those between ages 65 and 74. The longer a person lives, the more likely he or she is to experience health problems and functional limitations. The oldest old can experience four types of problems that can lead to challenges in managing their chronic illnesses. These include:

- Poor health status
- More than one chronic illness
- Functional and cognitive limitations
- Poor mental health status

Taken together, these factors can make members of this group less able and less motivated to manage complex chronic health needs on their own, highlighting the need for cooperation and collaboration among different kinds of medical providers, social

THE OLDEST OLD ARE A GROWING PART OF THE U.S. POPULATION.

In 2000, approximately 4.2 million people were ages 85 and older. The number is projected to grow to 6.1 million by 2010, and 7.3 million by 2020 (U.S. Department of Health and Human Services, 2007), reaching a projected 19 million by 2050 (U.S. Department of Commerce, 2008).

Although a relatively small share (4.4 percent) of the 65+ population lived in institutional settings in 2006, the proportion increased dramatically with age (1.3 percent for people ages 65–74; 4.4 percent for people ages 75–84 years, and 15.4 percent for the oldest old) (U.S. Department of Health and Human Services, 2007).

service providers, and formal and informal caregivers.²

- **The oldest old report poorer health status**

Among non-institutionalized older adults, in 2005, the oldest old were less likely to report being in excellent or very good health and more likely to report being in poor health (Figure 2.3).

- **The oldest old have multiple chronic diseases**

In 2005, the proportion of non-institutionalized middle old and oldest old who reported having multiple chronic illnesses was significantly greater than the proportion of their younger

counterparts. The slight difference in the experience of multiple chronic illnesses between the middle old and oldest old may be the result of the middle old succumbing to their illnesses before they reach age 85 (Figure 2.4).

- **The oldest old have more functional limitations than their younger counterparts**

Functional limitations impede individuals' ability to effectively navigate multiple providers and manage their care. For purposes of this report, physical functional limitations refer to those experienced by anyone in a family unit who reported having difficulty with any one (or

Figure 2.3:
Poor Health Status
Rises with Age



Source: AARP PPI analysis of Medical Expenditure Panel Survey, Household File, 2005.

Note: Data do not include people who live in institutions.

Figure 2.4:
Share of Older Adults
Reporting Two or More
Chronic Conditions



Source: AARP PPI analysis of Medical Expenditure Panel Survey, Household File, 2005.

Note: Data do not include people who live in institutions.

more) of the following: walking, climbing stairs, grasping objects, reaching overhead, lifting, bending or stooping, or standing for long periods of time (Agency for Healthcare Research and Quality [AHRQ], 2005).³ In 2005, among non-institutionalized older adults, those ages 85 and older reported having significantly more functional limitations than their younger counterparts (Figure 2.5).

- **The oldest old need more help with ADLs than their younger counterparts**

In 2005, among non-institutionalized older adults, those ages 85 and older were more than five times more likely than

their youngest counterparts and almost three times more likely than the middle old to anticipate needing assistance performing activities of daily living (ADLs) related to personal care—such as bathing, dressing, or getting around the house—because of an impairment or physical or mental health problem (AHRQ, 2005; Figure 2.6).

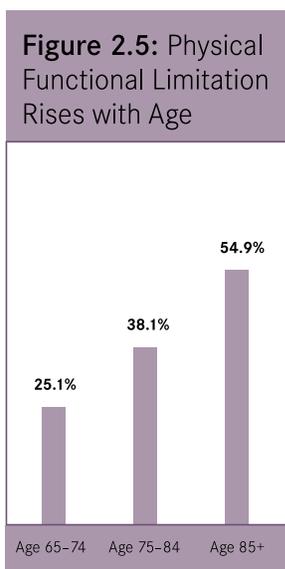
- **The oldest old need more help with IADLs than their younger counterparts**

When it comes to instrumental activities of daily living (IADLs)—activities related to independent living, such as using the telephone, paying bills, taking medications,

preparing light meals, doing laundry, managing finances, shopping, doing light or heavy housework, or using a telephone (AHRQ, 2005)—among the oldest old, in 2005, the percent reporting that they anticipated needing help or supervision for at least three months was almost seven times that of the youngest old and more than twice that of the middle old (Figure 2.7).

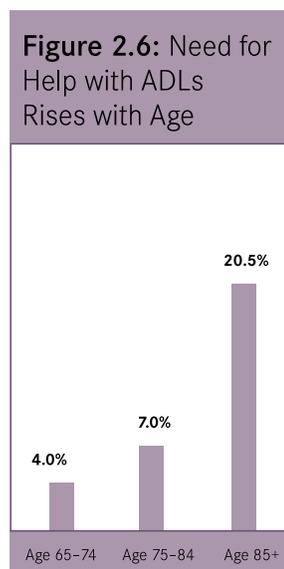
- **The oldest old have significantly more cognitive impairments than their younger counterparts**

The percent of non-institutionalized older adults reporting cognitive impairments (e.g., problems with memory,



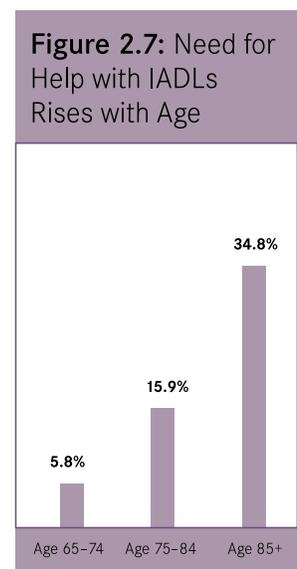
Source: AARP PPI analysis of Medical Expenditure Panel Survey, Household File, 2005.

Note: Data do not include people who live in institutions.



Source: AARP PPI analysis of Medical Expenditure Panel Survey, Household File, 2005.

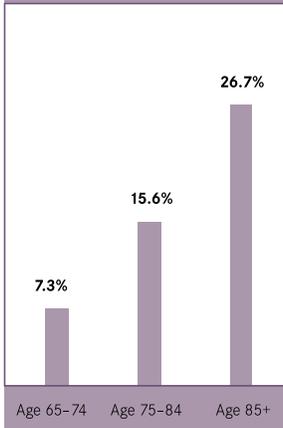
Note: Data reflect adults reporting needing help with ADLs for three or more months. Data do not include people who live in institutions.



Source: AARP PPI analysis of Medical Expenditure Panel Survey, Household File, 2005.

Note: Data reflect adults reporting needing help with IADLs for three or more months. Data do not include people who live in institutions.

Figure 2.8: Cognitive Limitations Rise with Age



Source: AARP PPI analysis of Medical Expenditure Panel Survey, Household File, 2005.

Note: Data do not include people who live in institutions.

perception, problem solving) increases with age, with the oldest old reporting limitations in their cognitive abilities at a rate almost four times that of the youngest old and almost twice that of the middle old in 2005 (Figure 2.8). For purposes of this report, cognitive limitations refer to whether an adult in the family experienced any one of the following: confusion or memory loss that interfered with daily activities, problems making decisions to the point of interfering with daily activities, or required supervision for their own safety (AHRQ, 2005). Cognitive limitations can significantly impede a person's ability to self-manage

“We have a nurse three days a week, two hours a day. That’s a big help. My mom is physically sick but her mind is great except she forgets her medications sometimes.”

[“Beverly” is a 49-year-old Philadelphia caregiver caring for her 74-year-old mother with stomach surgery, spinal fusion, chronic pain, congestive heart failure, hypertension, coronary artery disease, and multiple transitions (emergency room visits, hospitalizations, rehab therapy, and nursing home admissions).]

chronic conditions. For example, those with memory problems may be less able to manage taking multiple prescription medications on their own.

- **The oldest old experience worse mental health status than their younger counterparts**

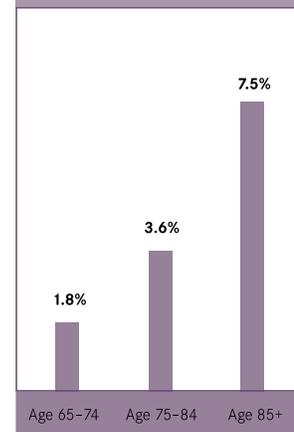
Alterations in mental health status, like depression and anxiety, can affect a person's motivation to actively participate in his or her health care and can be a significant barrier to effective self-management of chronic illness. For purposes of this report, mental health status was derived from subjective reports of how people viewed their own mental well-being (AHRQ, 2005). People were asked to rate their mental health status as being excellent, very good, fair, or poor. In 2005, among non-institutionalized older adults, the oldest old were more likely to report having poor mental health status (Figure 2.9) than their younger counterparts. A number of factors may account for poorer self-reported mental health status among the older age group, including the possible loss of a significant other, declines in health status of friends, possible mobility limitations, and a more acute awareness of mortality.

CARE AT THE END OF LIFE

In this last section, we take a look at care at the end of life. Although

medical progress has been made in diagnosis and treatment, many chronic conditions are associated with increased mortality rates and eventually lead to death. Sometimes, it becomes clear to clinicians from the course of illness that a patient is approaching the end of life and that curative measures intended to address the underlying illness offer less hope of success. In these cases, a variety of approaches are available, most of which include palliative care intended to ameliorate symptoms and comfort measures but may also include short-term treatment of acute conditions or curative care. While end-of-life care was once associated almost exclusively with terminal cancer, today people receive end-of-life care for a number of other conditions, such as congestive heart failure, other circulatory conditions, COPD, and dementia (MedPAC, 2008). Further, some experts have suggested that palliative and hospice care could be more widely embraced for many dying patients. However, these experts say that overly rigid quality standards and poorly aligned reimbursement incentives discourage appropriate end-of-life care and foster incentives to provide inappropriate restorative care and technologically intensive treatments. These experts note that hospitals, nursing homes, and home health agencies need

Figure 2.9: Poor Mental Health Status Rises with Age



Source: AARP PPI analysis of Medical Expenditure Panel Survey, Household File, 2005.

Note: Data do not include people who live in institutions.

stronger incentives to provide better access to palliative care and care coordination either directly, themselves, or by contract with outside suppliers of hospice services (Zerzan, Stearns, & Hanson, 2000; Hanley, 2004).

COST OF END-OF-LIFE CARE

Researchers have found that the cost of medical care during the last year of life accounts for 10 percent to 12 percent of total national health care spending (Emanuel, 1996). About one-quarter of Medicare spending occurs during the last year of life, unchanged from the early 1980s (Hogan, 2001). Some experts have suggested that some health care spending for patients near the end of life may

be unnecessary and that research has shown that the most aggressive treatment of late-stage chronic disease often does not prolong life and can decrease its quality (Wennberg, JE, et al., 2007). In addition, some say that aggressive treatment of late-stage chronic disease can give patients false hope.

However, identifying which health care services are unnecessary for dying patients can be difficult to do before spending occurs, and most clinicians prefer to err on the side of caution if they are unsure whether a particular intervention may have a beneficial effect on patient outcomes, either in terms of longevity or quality of life for the patient in question (Redelmeier & Tversky, 1990). Medicine is not an exact science, and it is rarely possible to predict an individual patient's time of death with mathematical certainty before substantial costs have been incurred.

In addition to difficulties identifying those near the end of life, a patient's preferences for care are difficult to predict and may change over time. Many people say that when you get very old (i.e., 100 years old), it would be nice to die in your sleep (*New York Times* [NYT], 2008). However, not everyone shares this view. In fact, it is not uncommon for people to cling to life even as it draws to a close. As Euripides, an ancient Greek, said, "If death draws near, none want to die, and age is no more a burden." In a study of hospitalized patients over 80 years old, researchers found that most patients prefer longevity to a higher-quality, shorter life, but preferences were highly individualistic. In a corollary finding, these researchers found that patient preferences could not be predicted by surrogates, such as family members, or by clinical or demographic information (Tsevat et al., 1998).

Although they may not be part of standard care during the last year of life, procedures that were rarely performed on very old patients 20 to 30 years ago have become increasingly commonplace even for patients into their 90s, including hip and knee replacements, heart surgery, pacemakers, and cataract surgery. In an example of one such case, a 99-year-old woman who had had a heart attack and was suffering from congestive heart failure (CHF) received an implantable cardiac defibrillator and was still alive and in relatively good health five years later (NYT, 2008). Her doctor argued that the operation, which was covered by Medicare at a cost of about \$35,000, costs less than repeated hospitalizations for heart failure and, even more notably, may have gained the patient one or more years of life.

IMPROVING END-OF-LIFE CARE

Studies suggest that coordination of end-of-life care could be substantially improved among providers, such as hospitals, nursing homes, home health agencies, and hospice (Lynn et al., 2000). Research suggests that increased use of hospice services may not yield net savings, at least not for Medicare (MedPAC, 2008), but other studies suggest that it is possible to expand access to palliative services and improve quality of care in ways that are financially feasible and acceptable to patients, families, clinicians, administrators, and payers (Byock et al., 2006).

However, studies have found that dying nursing home residents have limited access to palliative care and hospice (Zerzan, Stearns, & Hanson, 2000). In 1997, only 13 percent of hospice enrollees were in nursing homes and 70 percent of nursing homes had no hospice patients. Similarly, patients receiving home health services tend to underutilize hospice care (Hanley, 2004). While some nursing homes have expanded access to hospice services for their residents, hospice use varies by region, and rates of use tend to be associated with nursing home administrators' attitudes toward hospice and contractual obligation. As a result, questions remain about

how widely available hospice services are to nursing home residents regionally and locally and whether hospice services are being appropriately offered to nursing home and home care patients.

Models that promote better coordination of care delivery have been shown to improve quality and decrease cost of end-of-life care (Reb, 2003). Studies have also shown that intensive collaborative projects among a broad range of provider organizations in a well-defined geographic area can substantially improve the quality of end-of-life care through care coordination, advance care planning, pain management, and family support (Gould et al., 2007).

Studies have also shown that seriously chronically ill patients with COPD and CHF with less than a two-year life expectancy who receive home-based case management, care coordination, and palliative care together with active treatment reported lower symptom distress, improved functioning, and better legal preparation for end of life than patients who received usual care—although ER utilization was equivalent across groups (Aiken et al., 2006). Similarly, studies have found that end-of-life patients who receive assistance from a care coordinator with provider communication, care coordination, and emotional support experience greater satisfaction with care and communication and fewer problems with provider support and are more likely to complete an advance directive than patients receiving usual care. Depending on the type of reimbursement system and level of payment, a care coordinator may also lower costs (Engelhardt et al., 2006).

People with advanced diseases experience intense physical symptoms and emotional distress. For example, studies have found that 65 percent to 90 percent of cancer patients experience severe pain when cancer reaches advanced stages but that patients' end-of-life experience can be improved through adequate pain control when providers follow clinical practice guidelines for pain management (Rischer & Childress, 1996).

In addition to pain management, patients and caregivers report a number of needs that are often associated with end-of-life care, including information about the patient's condition and prognosis, communication with providers, coordination of care, access to end-of-life care, response time for acute care problems, and quality of life (de Vogel-Voogt et al., 2007; Mangan et al., 2003).

In conclusion, while it seems clear that improving care coordination near the end of life can improve care for patients with chronic conditions, the likely impact of such improvements on health care spending seems less clear.

ENDNOTES

- ¹ Quoted remarks and other findings reflect actual focus group findings. However, the names have been changed to protect the privacy of participants.
- ² Note that data reported in this section may vary from similar data on the same measures due to differences in how questions were asked and depending upon whether data sources did or did not include people living in institutions.
- ³ Respondents who answer “yes” are then specifically asked about difficulty: lifting 10 pounds; walking up 10 steps; walking three blocks; walking a mile; standing 20 minutes; bending or stooping; reaching over head; using fingers to grasp; and whether they expected to have difficulty with any of these activities for at least three more months (AHRQ, no date).

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3

Patients and Caregivers Report Problems with Care

A Significant Number of Patients Had Problems

Quality Problems More Likely among Certain Types of People

Caregivers Support People with Greater Use of Health Services

Quality Problems More Likely among Caregivers Who Feel Less Capable



AARP conducted two national surveys to learn more about chronic illness from the consumer perspective. One survey looked at the experiences of people 50 and older with chronic conditions. The second explored the experiences of caregivers over 45 for people with chronic conditions. Most of the findings from our surveys are new. Although other surveys of people with chronic conditions have asked similar questions, our questions and sample criteria are different from previous surveys (Harris Interactive, Inc. [Harris], 2000, 2008; Gallup Organization [Gallup], 2002; National Alliance for Caregiving and AARP, 2004).

“Our surveys revealed that a significant percentage of patients and caregivers have experienced serious quality-of-care problems, including medical errors and poor communication among providers, as shown in Figures 1 and 2.”

Our surveys targeted (1) people with selected (more serious) chronic conditions who also had a serious health episode, and (2) caregivers of people who needed assistance, had had a serious health episode, and received care from a health care facility within the past three years. Survey questions focused on experiences with these episodes of care, especially during “transitions” across health care settings (i.e., hospital inpatient, emergency room, nursing home, etc.) and returning home. The surveys

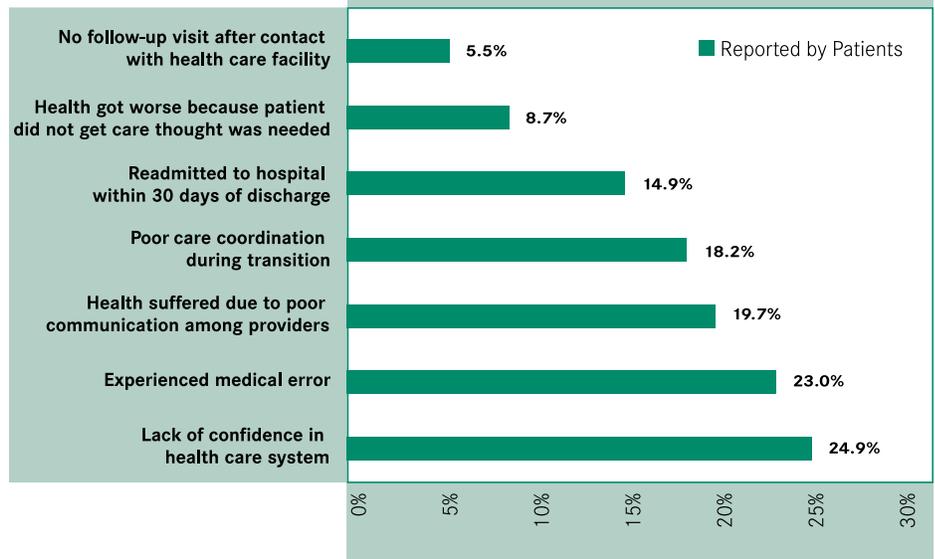
also focused on the use and need for services and support during transitions.

Respondents to both surveys report heavy use of the health care system, a finding consistent with the pattern of use described in Chapter 1. As we note in Chapter 2, strategies to help manage chronic illness should vary with people’s capabilities and needs.

In this chapter, we focus on problems that respondents reported. Our surveys revealed that a significant percentage of patients and caregivers have experienced serious quality-of-care problems, including medical errors and poor communication among providers, as shown in Figures 3.1 and 3.2.

The surveys found that people with chronic conditions who were most likely to report problems with the quality of their care also tended to have had worse transitions across health settings. These people also appeared less engaged and lacked confidence about their ability to manage their chronic conditions. They also tended to have characteristics consistent with worse health status, including more chronic conditions and need for help with arranging care. Interestingly,

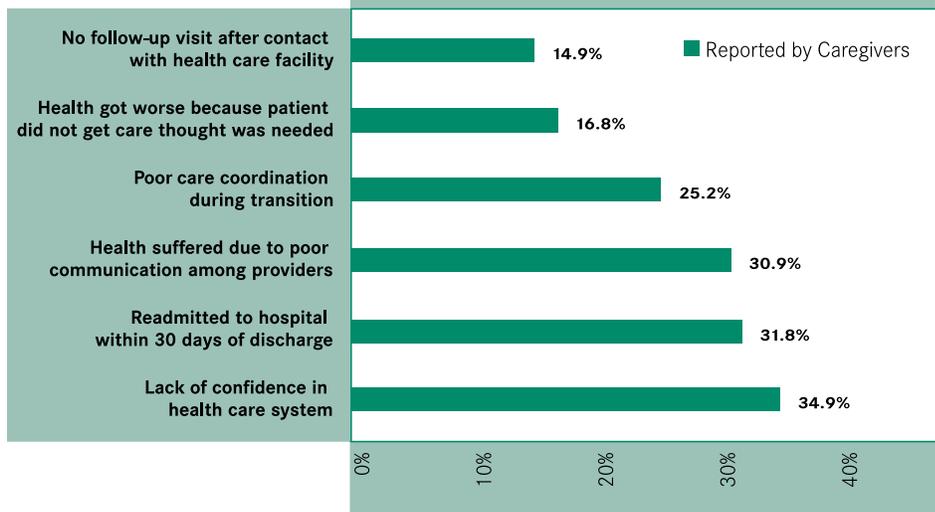
Figure 3.1
Poor Outcomes Reported for People with Chronic Conditions



Source: *Beyond 50.09 Survey Report*, AARP.

Note: Data include respondents age 50 and older. Sample size = 2,453

Figure 3.2
Poor Outcomes Reported for People with Chronic Conditions



Source: *Beyond 50.09 Survey Report*, AARP.

Note: Data include caregiver respondents. Sample size = 978

people with more frequent episodes of care reported fewer problems, suggesting that they had learned from their experiences.

The caregiver survey finds that the people they cared for use health care services more intensely and receive more support than respondents with chronic conditions, and that some caregivers do not feel capable in their role. Caregivers who do not feel capable are more likely to report that their care recipients had poor quality of care.¹ Survey samples were independent, and respondents with chronic conditions were not linked with caregiver respondents.

These findings suggest the following:

- Clinicians need to assess the level of preparation and engagement of patients with chronic conditions to manage their own care and the extent to which caregivers feel capable of helping their care recipients.
- Providers should target patients with chronic conditions and their caregivers who report a lack of engagement for additional support, such as care coordination and community support services.
- Clinicians should actively “coach” patients (and their caregivers) who report a lack of engagement on how to

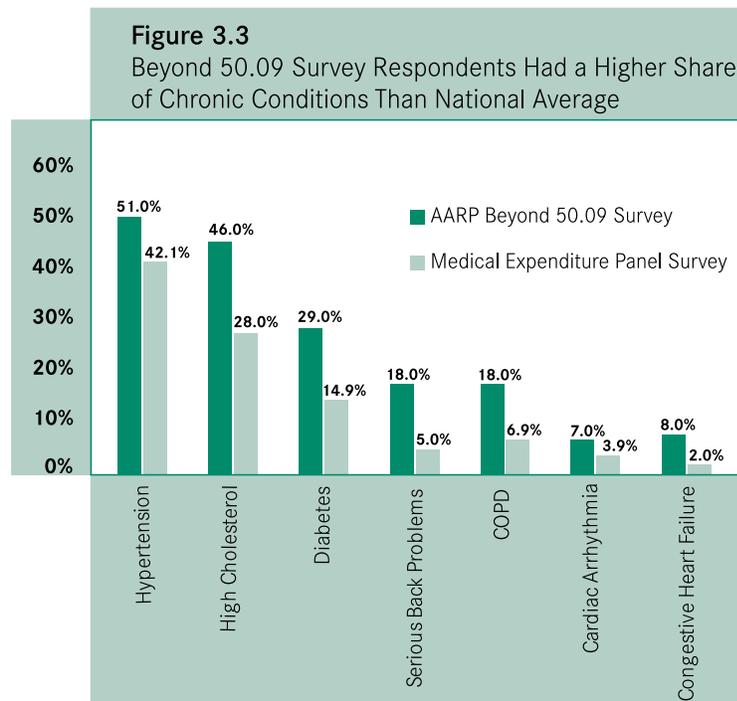
manage and monitor their chronic conditions.

SURVEY RESPONDENTS HAD MORE CHRONIC CONDITIONS THAN AVERAGE

On average, our survey respondents had 3.6 chronic conditions, compared with 2.5 conditions among people over 50 with at least one chronic condition in a 2005 federally sponsored health care survey known as the Medical Expenditure Panel Survey (MEPS).² This finding is consistent with our survey method to include only

people with selected (more serious) chronic conditions who had experienced at least one transition across health care settings over the last three years—a survey method likely to make our sample sicker than national MEPS respondents who could have had any chronic condition (Figure 3.3).

Hypertension, high cholesterol, and diabetes were among the most common chronic conditions. Over a three-year period, survey respondents used health care services in both facilities and ambulatory settings.



Source: *Beyond 50.09 Survey Report*, AARP; Johns Hopkins Bloomberg School of Public Health analysis of Medical Expenditure Panel Survey, 2005

Note: Data include adults age 50 and older. *Beyond 50.09* survey respondents had at least one serious episode in the last three years. The manner in which chronic conditions were defined differed between surveys.

Four out of 10 (39 percent) had three or more admissions or other encounters with a health care facility.

For their most serious health episode, 72 percent received care in a hospital, and 39 percent visited an emergency room.

Respondents visited their usual care provider (primary physician or nurse practitioner) an average of 16.2 times and a specialist an average of 12.7 times.

One in five respondents saw specialists 17 or more times (Figure 3.4).

About a third (35 percent) of respondents with chronic conditions received paid assistance, such as home health care or rehabilitation therapy.

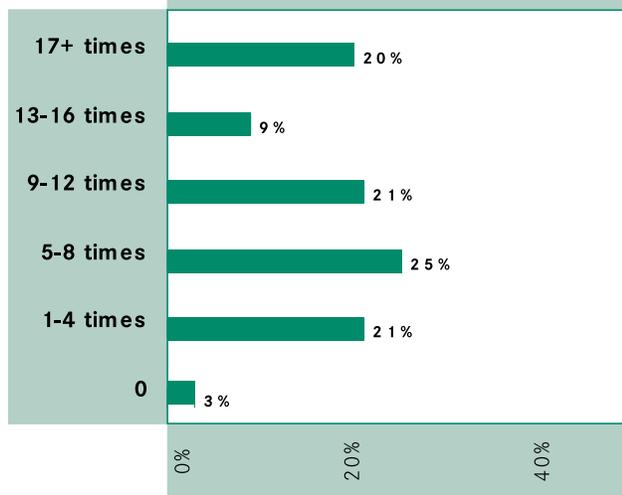
Among respondents ages 50+ with chronic conditions and a serious health episode, two in five (43 percent) said that their health was *fair* or *poor* (Figure 3.5).

The health of people with chronic conditions in our survey was generally comparable or worse than the health of respondents to other surveys. However, it is important to note that other surveys did not use

the same sample selection criteria. Other surveys have found that self-reported health status ranged from a low of 12 percent *fair* or *poor* for people over age 18 (Harris, 2000) to 24 percent *fair* or *poor* for people over age 50 (Current Population Survey, 2008). However, our respondents reported better health status than a Gallup survey that reported a high of 58 percent *fair* or *poor* for people of any age with a chronic condition that interfered with daily activities (Gallup, 2002).

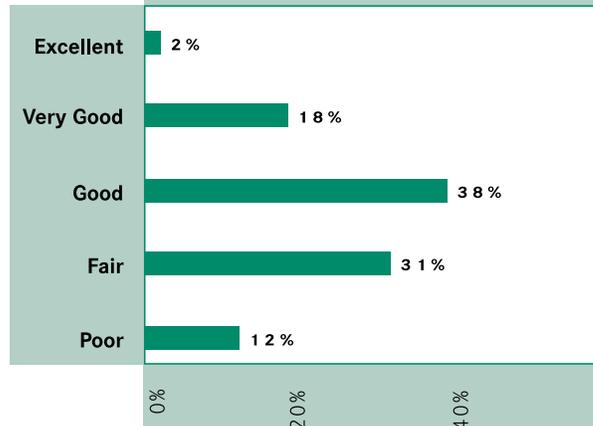
More than half (57 percent) of respondents with chronic conditions said that their chronic

Figure 3.4
Most People with Chronic Illness Have Many Specialist Visits



Source: *Beyond 50.09 Survey Report*, AARP.
Note: Data include respondents age 50 and older reporting seeing a medical specialist in the past three years. Sample size = 2,453

Figure 3.5
People with Chronic Illness Report Differing Health Status



Source: *Beyond 50.09 Survey Report*, AARP.
Note: Data include respondents age 50 and older reporting perceived health status. Sample size = 2,453

condition limits their daily activities. One in three (33 percent) said that they needed assistance with a variety of health-related activities, such as taking medications, making medical-related appointments, understanding information from health care providers, or arranging transportation. Of the respondents with chronic conditions who needed help managing their conditions, three-quarters (76 percent) had an unpaid caregiver, such as a relative or friend. This informal help included making or getting to health care appointments, understanding information from a health care provider, and managing medications.

A SIGNIFICANT NUMBER OF PATIENTS HAD PROBLEMS

One in five respondents with chronic conditions reported that they had problems getting timely care when sick (22 percent) and did not think that their care was well coordinated (19 percent). One in four (26 percent) lacked confidence in the health care system. Significant shares of respondents also reported experiencing:

- Medical errors (23 percent); of these, a majority (61 percent) said that the problem was major
- Unnecessary medical tests (16 percent)
- Potentially unnecessary hospital readmissions (15 percent). Hospital readmissions suggest potential quality-of-care problems, for example, being discharged too early or experiencing inadequate follow-up care.

Less common than other problems were reports of unneeded surgery (3.5 percent) and infections during hospitalization (10 percent). Although based on different sample selection criteria, other surveys reported similar rates of medical errors (16 percent), readmissions (18 percent), and unnecessary medical tests (20 percent) (Harris, 2008).

Almost one-fifth (18 percent) of our chronic condition survey respondents said that, within the past three years, they did not receive health care attention for a condition that they thought was serious. Almost half said that their health had gotten worse because of it. Worsening health status for not receiving needed care was significantly associated with lower household income but not with other factors.

The most common reason given for not receiving care was that the respondents' provider told them not to be concerned (34 percent). However, many respondents said that they could not afford care, or could not find a provider or get an appointment.

Some survey respondents reported not following through on treatment plans even though they had received care. More than a quarter (27 percent) said that they had *not* done something recommended by a health care professional, such as fill a prescription (32 percent), make a healthy lifestyle change (18 percent), make a follow-up appointment (18 percent), get a medical test (12 percent), or have a surgical procedure (4 percent).

It is interesting to note that the most common reason for not following a clinician's advice was that the patient disagreed with the clinician's recommendation (32 percent).

Caregiver respondents reported more access and quality problems than we found in the survey for people with chronic conditions. As noted earlier, respondents in these two surveys were not linked in any way, and selection criteria were different. Of particular importance, one in four (25 percent) of the caregiver respondents reported that their care recipients did not receive health care attention for a condition they thought was serious. This is higher than reported by "patient" respondents, 18 percent of whom said that they did not receive health care

attention for a serious problem. The difference may be due to poorer health status of the people caregivers help, or that, as observers, the caregivers were in a better position to identify problems in the health care system.

REPORTS ABOUT COMMUNICATION AMONG PROVIDERS

As suggested in Chapter 4, which describes ways of improving chronic care, clear, timely and comprehensive communications among health care providers and between providers and their patients, as well as their caregivers, is an important part of care coordination. Poor communications can contribute to rough transitions across health care settings, dropped “handoffs” of patients between providers, and patients’ suffering worse outcomes because of lack of care coordination.

One in five respondents (21 percent) to the chronic condition survey said they felt that their providers (both usual care provider and specialists) did not do a good job of communicating with each other about their condition or treatment. Younger patients (ages 50–64) were more likely to report poor communication than older ones (ages 65+). One in four respondents (24 percent) with chronic conditions said they had received conflicting information from two or more providers, a larger percentage than the 17 percent found in an earlier survey (Harris, 2000). One-fifth (20 percent) of respondents with chronic conditions indicated that their health had suffered at some point because their providers were not communicating with each other about the patient’s condition or treatment.

Poor communication may have contributed to our survey finding (above) that 32 percent of respondents with chronic conditions did not follow their clinician’s advice because they disagreed with it. Although our survey did not ask this directly, we might infer that people are less likely to follow advice that has not been clearly or convincingly communicated.

Other issues reported by respondents included the following:

- Provider did not have all the needed information when the patient arrived for a visit (30 percent)
- Provider did not explain matters in a manner the patient could understand (15 percent)
- Respondent was not told the purpose of a new medication (9 percent).

The pattern of responses among caregivers was similar.

Other surveys have also found that 24 percent of providers surveyed often lack needed information when the patient arrives for an appointment (Harris, 2008).

QUALITY PROBLEMS MORE LIKELY AMONG CERTAIN TYPES OF PEOPLE

Researchers studying the care of people with chronic conditions have identified two related aspects of care that they believe are important to good outcomes (Naylor et al., 1994; Coleman, Mahoney, & Parry, 2005; Hibbard et al., 2004). One, called the care transitions measure (CTM), captures whether the provider appropriately prepared patients or caregivers to manage a patient’s condition during and after a transition—leaving a hospital or other health facility. The other, called the patient activation measure (PAM) captures the extent to which patients feel engaged and confident in taking care of their condition.

The care transitions measure, or CTM, combines responses to three questions about a patient's comprehension and care in order to determine a patient's

- (1) Understanding of self-care responsibilities in the post-hospital setting
- (2) Understanding of the purpose of each medication taken
- (3) Having their personal preferences incorporated into the care plan

CTM scores are ranked as low, medium, or high—indicating that the quality of transitional experience was poor, fair, or good. The CTM has been independently tested and validated (Coleman, Mahoney, & Parry, 2005) and shows a relationship between the quality of care coordination received by patients following discharge or a visit to a health care facility and the likelihood of a subsequent emergency room visit or readmission (Parry, Mahoney, Chalmers, & Coleman, 2008).

Through our surveys, we wanted to learn whether people who reported more problems in the health care system tended to have been adequately prepared to manage their condition after a transition or were less engaged in handling their health, generally.

We found that more problems are reported by people who are less engaged. We also found that people reporting higher rates of medical errors tended to be younger, more educated, unemployed or retired, with inadequate health insurance, with poorer reported health status, and with five or more chronic conditions.

TRANSITIONAL CARE

Health services literature marks transitional care—the care and support services that individuals receive after discharge from a hospital, emergency room, or other health care facility—as an important juncture in the health care delivery system (Naylor et al., 1994; Anderson & Horvath, 2002). At this time, patients may be particularly vulnerable to care quality and safety problems, as they may be inadequately prepared to care for themselves when they leave a health care facility and may not understand their care needs, including the purpose of their medications.

Because of these problems with transitional care, many patient care needs are not fully met, and health care spending is higher, as people with chronic conditions are more likely to be readmitted to a health care facility and suffer poor clinical outcomes.

We used two approaches to measure the quality of transitional care. We asked respondents directly whether they thought their care, or care of the person they were helping, had been well coordinated. We defined “good care coordination” as a situation in which providers keep in touch with each other to ensure that their patients are getting the care they need, and patients and caregivers have all the information they need. We also used the care transitions measure, which focuses on patient knowledge and preferences.

When asked for a direct assessment of their experiences, one in five respondents (18 percent) with chronic conditions said that their transitional care was not well coordinated. Our other measure (CTM scores) showed that a similar proportion (15 percent) had a poor transitional experience. Other indicators of potentially poorly coordinated transitions from our survey were that about one in seven people with chronic conditions did not receive a follow-up appointment, or, if they did, the appointment was more than four weeks after they left the

facility (14 percent), or they returned to a facility for care within 30 days (15 percent).

Among people with chronic conditions who had a poor transitional experience, almost a quarter had more than five chronic conditions. After controlling for demographic and other factors, the characteristics significantly associated with a poor transition were (1) a greater number of chronic conditions; (2) poorer health status; and (3) less education.³ Although these respondents were sicker than the other respondents, they had fewer office visits, suggesting less experience navigating the health care system and a less active relationship with their primary clinician.

Predictably, the respondents with chronic conditions experiencing poor transitions were more likely to be readmitted to a health care facility within 30 days of discharge. Nearly a quarter (23 percent) of people with low CTM scores said that they were readmitted to a health care facility within a month of discharge. Higher readmission rates were also associated with poor health status, needing assistance with patient care coordination activities, being male, and low ability to navigate the health care system.⁴

PATIENT ENGAGEMENT

Studies suggest that people who are more knowledgeable, skilled, and confident about handling their chronic conditions, whom we refer to as “engaged,” are better able to manage their own care, promote their own health, and make better decisions affecting their condition. Such people experience fewer health crises and functional status declines. Moreover, gains in level of engagement are associated with improvements in health-related behaviors (Hibbard, Mahoney, Stock, & Tusler, 2007).

Our survey found that lower patient engagement is significantly associated with experiencing more problems in the health care system. This finding suggests that clinicians need to assess people’s level of engagement. Care coordination programs should target resources and support to patients who are less engaged and confident about their ability to manage their own care.

Based on PAM scores, we found that 71 percent of respondents with chronic conditions were in the highest two levels of engagement (levels 3 and 4), while 29 percent were in the two lowest levels (levels 1 and 2).

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Hospitals, other health care facilities, home health agencies, health plans, and quality improvement organizations in more than 15 countries use the CTM to assess and improve the quality of care coordination services and reduce unnecessary readmissions of patients with complicated care management needs. It also is used for high-risk patients, including adults with chronic conditions, frail elderly persons, and cancer patients.

The patient activation measure (PAM), developed by Professor Judith Hibbard and colleagues (Hibbard et al., 2004), asks respondents a series of 13 questions about their

- Knowledge/understanding of their health problems and what causes them, what each of their prescribed medications do, and what treatments are available for their health problems
- Skills in taking responsibility for managing their own health, taking an active role in their own health care, and determining their ability to figure out solutions to new problems and to maintain lifestyle changes
- Confidence in their ability to prevent or decrease problems with health, their ability to tell a provider their concerns, their ability to follow through on medical treatments, and their ability to maintain lifestyle changes

LOW ENGAGEMENT SIGNALS PROBLEMS

People who were less engaged were worse off than others. Respondents with chronic conditions who were the least engaged were sicker than other respondents. Respondents with the lowest PAM score were more likely to have more than five chronic conditions, chronic conditions that limit daily activity, poor health, and more than 15 visits to their usual care provider. We found that survey respondents with chronic conditions who were less engaged were more likely to need assistance with patient care coordinating activities. Less engaged people with chronic conditions tended to be poorer, have less education, and report that their insurance coverage was inadequate.

People who were less engaged reported more problems. Among respondents who were the least engaged, we saw a pattern of responses about their experiences with health care that raised concerns about their quality of care. This group appeared less likely to look out for themselves. They were more likely to say that

- They needed health care attention for a serious condition but did not get it.
- Their health got worse because they did not get the health care they needed.
- They were less likely to follow their provider's advice.
- They had experienced a medical error.

Except as otherwise noted, most of the differences in level of engagement for people with chronic conditions remained after controlling for most demographic and socioeconomic factors (age, gender, race, education, income, health insurance status). These findings were consistent with those of another recent national survey (Hibbard & Cunningham, 2008).

ENGAGEMENT IS RELATED TO NOT GETTING CARE

Not getting care for a needed condition varies by level of engagement. Half (49 percent) of respondents with chronic conditions who were the least engaged (had the lowest PAM score) reported that they needed health care attention for a serious condition but did not get it, compared with only 11 percent of respondents in the highest engagement level. In addition to having a low PAM score, a number of other factors were significantly associated with not getting needed care, including having chronic conditions that limit daily activities, having worse health status, having insufficient health insurance, and being employed. However, even after

controlling for these and other factors (age, gender, education, number of chronic conditions), the relationship of engagement to reporting not getting attention for a serious condition was still significant.

Engaged and unengaged people give different reasons for not getting care. We found interesting differences in the reasons given by people who thought they did not get needed health care for a serious condition:

- Less engaged people with chronic conditions were more likely to cite lack of transportation as the reason for not receiving care. This is consistent with the notion that people at low engagement levels are less engaged in their care and vulnerable to obstacles that can derail efforts to care for their own health.
- More engaged respondents with chronic conditions were more likely to cite a family member saying not to be concerned as the reason for not seeking care.

ENGAGEMENT IS RELATED TO HEALTH AND MEDICAL ERRORS

People who were not engaged were more likely to report that their health got worse because they did not get the health care they needed. This characteristic was also associated with having chronic conditions that limit daily activities and needing assistance with care coordination activities.

Experiencing a medical error was more likely among less engaged people with chronic conditions. Overall, one in four respondents (23 percent) with chronic conditions said they had experienced a medical error. The ratio was much higher for those who were less engaged—more than one-third (36 percent) reported experiencing a medical error. However, the ratio was lower for those who were highly engaged—one in five (19 percent) reported experiencing a medical error. The reason for this difference may be that less engaged people have less confidence in addressing problems, or that more engaged people are more likely to detect problems before they become errors.

Reporting a medical error was also associated with other factors, including having more chronic conditions, having more office visits, having chronic conditions that limit daily activities, needing assistance with care coordination activities, poor health status, having insufficient health insurance, and having more education. Even after controlling for a number of other factors (age, gender, employment), respondents with

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Based on their combined responses to these questions, respondents receive a single PAM score and are divided into four progressively higher categories of activation or engagement, level 1 being the lowest and level 4 being the highest:

- Level 1: People do not feel confident enough to play an active role in their own health and tend to be passive recipients of care.
- Level 2: People lack confidence and an understanding of their own health or recommended regimen.
- Level 3: People have the key facts and are beginning to take action but may lack confidence and the skill to support their behaviors.
- Level 4: People have knowledge, skills, and confidence to play a significant role in their care, and have adopted new healthy behaviors but may not be able to maintain them in the face of stress or health crises.

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The PAM for people with chronic conditions has been tested and validated repeatedly (Hibbard et al., 2004). The PAM for caregivers was adapted for first-time use in our caregiver survey. Based on expert review, scores from the PAM for caregivers appeared consistent with previous research findings, which have validated the PAM for people with chronic conditions.⁵

Our characterization of PAM scores differs somewhat between surveys. We refer to PAM scores of people with chronic conditions in terms of level of engagement. However, caregiver PAM scores have a slightly different meaning. The caregiver PAM asks about the caregiver's knowledge, skill, and confidence for managing the health of the care recipient—e.g., “When all is said and done, I am the person responsible for managing my relative's/friend's health” or “I am confident that I can follow through on medical treatments I need to do for my relative/friend at home.” Responses indicate how able or competent caregivers feel about managing the health and health care of their care recipients. Thus, for caregiver PAM scores, we refer to level of ability or competence as a caregiver.

chronic conditions who had lower engagement levels were more likely to experience a medical error.

ENGAGEMENT AND PROVIDERS

Not following providers' advice also was more common among people who were less engaged. Not following their providers' advice was also significantly associated with having more office visits, having chronic conditions that limit daily activities, having insufficient health insurance, and being employed. Even after controlling for a number of other factors (age, gender, education, employment), respondents with chronic conditions who had lower levels of engagement were less likely to comply with their providers' advice.

The reasons for not following providers' advice differed among more engaged and less engaged people. Even though more engaged respondents with chronic conditions were more likely to follow their providers' advice, some did not. **The reason most often given was that they (personally) disagreed with their provider's recommendation.** This explanation would seem consistent with people being both more knowledgeable about their condition(s) and also more inclined to question their providers.

Less engaged respondents with chronic conditions were less likely to take steps to resolve problems when they thought their providers were not communicating well about their conditions. Overall, one-fifth (20 percent) of respondents felt their health had suffered because their providers were not communicating well about their condition. Almost half of all respondents with the lowest level of engagement (lowest PAM score) reported having such problems, while only one in eight (13 percent) of the most engaged respondents reported this problem.

Other factors significantly associated with declines in health due to poor provider communication included having chronic conditions that limit daily activities, having insufficient health insurance, being employed, and being a woman. However, having less engagement was still significantly associated with this problem even after controlling for a number of other factors (age, education, health status, number of chronic conditions, and number of office visits).

RELATIONSHIP BETWEEN TRANSITIONS AND ENGAGEMENT

We found that less engaged respondents had lower transition scores and were more likely to be readmitted to a facility within 30 days. Overall, respondents with chronic conditions who were readmitted to a facility

within 30 days after discharge were more likely to be the least engaged (have the lowest PAM score), whereas those who were not readmitted were more likely to be the most engaged (have the highest PAM score).

Readmission was also associated with needing assistance with patient care coordination activities, having poorer health status, and being male. However, having a lower engagement level was still significantly associated with being readmitted within 30 days after controlling for a number of other factors (age, education, number of chronic conditions, number of office visits, adequacy of health insurance, and CTM score).

CAREGIVERS SUPPORT PEOPLE WITH GREATER USE OF HEALTH SERVICES

Caregivers are a critical part of the care of people with multiple chronic conditions, particularly those patients who have functional and cognitive impairments. Caregivers tend to help people who use more services and have more support needs than those who were studied in the survey of people with chronic conditions.

For the purposes of this study, caregivers are defined as men or women ages 45 and older who provided unpaid care in the past three years to a spouse or partner, friend, or relative ages 50 and older who experienced a transition from a health care facility other than a permanent nursing home. The care provided was helping someone with health or non-health needs, including medication management, scheduling medical appointments, transportation, household chores, or checking in from time to time. Men are no less likely than women to provide care or assistance to a friend or family member. The average caregiver age is 59, and one in four are 65 years or older, which is not surprising since our selection criteria required caregivers to be at least age 45.

We find that many caregivers describe their own health as *fair* or *poor* (21 percent), which is comparable to the health of caregivers in previous surveys of caregivers over age 18 (17 percent *fair* or *poor*) (National Alliance for Caregiving and AARP, 2004).

Caregivers were asked to think about the most serious health episode or series of health-related events for the one person they assisted most in the past three years. The largest proportion (55 percent) of caregivers reported that the most recent serious health episode lasted for more than a month, and these episodes were considered by most caregivers to be very serious or life threatening. One in five caregivers (20 percent) reported that the

(CONTINUED)

Although we report attributes of respondents with both low and high PAM scores, we focus primarily on those with the lowest PAM scores because those respondents were most likely to need and to benefit from some type of additional assistance. Respondents with the highest PAM scores did not necessarily have opposite characteristics of those with the lowest PAM scores.

most serious event lasted between two to three weeks, and one-quarter (25 percent) said that the event lasted for one week or less.

Caregivers reported that the individuals they were helping were sicker and made greater use of health care services than we found in our survey of people with chronic conditions (Table 1). As noted earlier, respondents in these two surveys were not linked in any way, and selection criteria were different. Caregivers reported that three-quarters (74 percent) of their care recipients reported *fair* or *poor* health, compared with two in five (43 percent) of the chronic condition survey respondents. The people helped by the caregiver respondents made more visits to their usual care provider and to specialists. In addition, they were almost four times more likely to have been admitted to or visited a health care facility.

QUALITY PROBLEMS MORE LIKELY AMONG CAREGIVERS WHO FEEL LESS CAPABLE

Having a caregiver does not necessarily prevent poor care coordination. Furthermore, having a caregiver who feels less able or capable is associated with worse experiences of the health care system for their care recipients with chronic diseases. These findings suggest that care coordination

Table 1. People with Caregivers are More Likely to Use Health Services		
Use of health care services over 3 years	Survey Group 1	Survey Group 2
Average visits to usual care providers	16 visits	28 visits
Average visits to specialists	12 visits	23 visits
Average admissions and visits to health care facility	3 admissions and visits	11 admissions and visits
Hospital admissions for most serious health episode	72% admitted	81% admitted
Emergency room visits for most serious health episode	39% visited	44% visited

Source: *Beyond 50.09 Survey Report*, AARP.

Note: There were two groups of survey respondents: (1) people with chronic conditions and (2) caregivers responding about people with chronic conditions who they help. Some of the respondents in the first group had caregivers.

strategies might focus on helping to support caregivers.

Among caregivers who felt the least capable in their role (those with the lowest PAM level), their care recipients were more likely to have had poorly coordinated care and experience a poor transition following discharge from a health care facility. People with the poorest health were also likely to have caregivers who felt the least able to manage the caregiver role. This finding is not surprising, since the role of caregiver is likely to be more demanding and time consuming for sicker patients with greater health care needs.

In addition, caregivers who felt least capable reported that their care recipients were *less likely* to have had

- Timely care
 - Appropriate referrals
 - Preventive and screening services
- and were *more likely* to have had
- Unnecessary medical tests
 - Conflicting information from providers
 - Problems with poor provider communication
 - Poorer health because providers were not communicating about them

Not surprisingly, these caregivers said that they lacked confidence in the health care system.

People supported by the most capable caregivers were more likely to have excellent or very good health status and have visited their

usual care provider and specialists frequently (at least 10 times for usual care and at least 17 times for specialists in the past three years).

The opposite relationship is also present in our survey results. We found that people supported by these highly capable caregivers were more likely to have had their care well coordinated and a good transition after leaving a health care facility. These more capable caregivers were also more likely to report that they understood the provider's explanations and never had difficulty finding needed health care information. Finally, these most capable caregivers were more likely to say they had confidence in the health care system.

What are the characteristics of more capable caregivers? We found that younger caregivers (ages 45–54) felt the least prepared and able to manage the health of someone else, while older caregivers were more likely to feel capable. Higher sense of capability was associated with being female, Hispanic, and less education and income, while lower capability was associated with being male, white, and higher education and income.

Our findings suggest that there are important differences in how caregivers perceive their role. Some caregivers seem to embrace it, while others may assume it reluctantly. Although the PAM used in our caregiver survey was designed to directly assess how capable people feel in the caregiver role, it may also reflect, indirectly, how willing caregivers are to assume their role.

Not surprisingly, caregivers feel less capable about managing the health and care of their care recipients than they might feel about themselves. Respondents with chronic conditions tend to be less engaged than the general public, which is as a group healthier than our respondents.

DETAILED METHODOLOGY

AARP conducted two national opinion surveys: (1) one of people with chronic conditions, and (2) one of unpaid family caregivers. The respondents to the two surveys were independent samples—that is, the respondents in the caregiver survey were not linked to the respondents in the chronic condition survey.

The first group we focused on included people ages 50+ who had at least one doctor-diagnosed chronic illness that has lasted for 12 months or more. From this group we selected people who had “more serious” chronic illnesses.⁶ In addition, to understand the impact of transitions across health care settings on people with chronic conditions, we screened the sample to make sure each person had had at least one episode in the past three years that resulted in their being admitted to or visiting a hospital, rehabilitation facility, nursing home, emergency room, or outpatient clinic such as an ambulatory surgery center or urgent care setting.

The second group we focused on included people ages 45+ who were currently providing or had provided unpaid care to a friend or relative ages 50+ and, within the past three years, had experienced at least one transition from a health care facility, as described for respondents in our chronic illness survey.

We defined “transition” in this way because episodes involving a health care facility are more likely than office visits to involve serious health care conditions and often require that patients or caregivers understand and perform follow-up care and related care coordination activities.

Examples of unpaid care provided by caregivers include helping with health-related needs (such as medication management or giving injections, scheduling medical appointments, or changing the dressing on wounds),

helping with household chores, managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. The caregiver providing the assistance did not have to live with the care recipient.

The surveys were designed by AARP staff and fielded by Knowledge Networks, a national opinion survey research firm. Our survey of people with chronic conditions was conducted between August 22 and August 27, 2008, while our survey of family caregivers was conducted between October 3 and October 15, 2008.

The surveys were conducted over the Internet by Knowledge Networks. Participants were recruited from a national household panel based on a random-digit telephone dialing methodology that included non-Internet households that Knowledge Networks equipped with a Web device for participants without computers or Internet connectivity. Knowledge Networks routinely offers respondents nominal compensation of about \$5 to \$10 for their participation. Knowledge Networks' sampling operations have been tested by independent research organizations to confirm that individuals recruited for their surveys are representative of the U.S. population. The analysis weighted samples to reflect national demographic distributions of the adult population based on age, sex, race, ethnicity, and education. Knowledge Networks obtained certain demographic and clinical information from these individuals in screenings that were independent of our surveys.

The survey of chronically ill individuals had a high overall panel cooperation rate (72 percent); less than 1 percent of respondents declined to answer any particular question. The sample of respondents with chronic conditions who met our screening criteria totaled 2,453. The margin of sampling error for the survey of chronically ill was +/- 2 percent.

The panel cooperation rate for the survey of caregiver respondents was 63 percent, with 978 meeting our screening criteria. This analysis also weighted samples to reflect national demographic distributions of the adult population based on age, sex, race, ethnicity, and education. The margin of sampling error for the caregiver survey was +/- 3 percent. However, because not all caregivers were necessarily involved with all aspects of the recipient's health care, caregiver respondents had a high "don't know" response rate to some survey questions. For more complete results, see survey findings described elsewhere (*Beyond 50.09 Survey Report*).

STUDY STRENGTHS AND LIMITATIONS

While our surveys are weighted to be nationally representative, our results should not be used to extrapolate numerical estimates, nationally. Our surveys were not expressly designed for this purpose, our screening criteria excluded some chronic conditions, and more detailed information would be necessary to apply post-stratification estimating techniques.

Our surveys did not require oversampling to obtain representative samples of ethnic minorities. Although care was taken to minimize selection bias, non-English speakers may be underrepresented. In addition, severely cognitively impaired individuals may be underrepresented in the survey of people with chronic conditions. On the other hand, the caregiver survey may include information provided by caregivers on severely cognitively impaired individuals who were care recipients.

Some media organizations have questioned the quality and reliability of online surveys as less "rigorous" or "scientific" than random telephone surveys. However, experts assert that online surveys can be at least as reliable

as, and in some cases more reliable than, telephone surveys (Taylor, 2007). For instance, the response rate was 37 percent for an earlier random telephone survey polling people who had chronic conditions that interfered with daily activities (Gallup, 2002). However, our panel cooperation rate was 72 percent for respondents with at least one chronic condition and a transition across settings, and 63 percent for caregiver respondents of people who needed assistance (98 percent of whom had received care one or more times from a health care facility within the past three years).

Samples of respondents with chronic conditions and caregiver respondents were not matched. We did not ask our caregiver respondents about the nature of their care recipient's illness (acute versus chronic diagnosis), and so the type and seriousness of health conditions among respondents may vary between our surveys. However, we asked both groups similar questions to provide us their perspectives on their experience with the health care system.

These surveys represent snapshots in time, rather than trends over time.

For the purposes of this study, we asked respondents to think about their (or their care recipient's) most serious health episode over the past three years. Although we realize that some people may have less accurate recall over a three-year period compared to a one-year period, we selected this time frame to increase the probability that the respondent had had a health transition experience and to improve our chances of obtaining an appropriate sample size. While forgetfulness may not be random, if anything, problems are more likely to be underreported than overreported. Readmissions may have been related to natural progression of illness rather than poor care coordination. Of course, respondents may have misunderstood some questions.

CONCLUSION

Many people with chronic conditions and their caregivers encounter problems with the health care delivery system. In theory, health professionals and other providers assume the role of ensuring that smooth transitions occur. However, as we point out in other chapters, the locus of responsibility for this activity is not always clearly assigned, and financial incentives do not encourage providers to perform the role of care coordinator. As we describe in the following chapter, many people with chronic conditions and their caregivers could benefit from improved transitional care and other care coordination services.

Providers should use techniques such as “coaching” to help people with chronic conditions and their caregivers better understand how to manage and monitor their conditions. Specifically, people with chronic conditions and their caregivers need to understand the purpose of their medications, the tasks they will be responsible for managing, and their overall plan of care, particularly with those who are experiencing a transition across health care settings. The preferences of individuals and caregivers need to be taken into account when developing the plan of care. Failure to adequately address these factors can contribute to people failing to manage their own care or receive follow-up care and otherwise experiencing problems that can lead to worse health.

Clear, timely, and comprehensive communication among providers and between providers and their patients is critical, particularly for those with chronic conditions (and their caregivers), because of their frequent encounters with the health care system and their use of multiple medications. A hallmark of many care coordination

programs is to improve the flow of information among providers and to those with chronic conditions and caregivers to facilitate better management of chronic care.

Monitoring the quality of transitional experience using CTM scores or similar measures could help to improve the quality of care for people with chronic conditions; possibly, the health outcomes they experience; and, ideally, the efficiency of the health care system. Additional care coordination support could target people who are less engaged and who have caregivers who feel less capable of using these assessment tools.

Greater attention should be focused on caregivers when patients are discharged from health care facilities and during transitions because, in many cases, caregivers sometimes understand more than their care recipients. With appropriate consideration for patient privacy and consent, ensuring that caregivers understand instructions, medications, and responsibilities for the people they are caring for could smooth transitions and reduce avoidable readmissions.

Caregivers also need support. A substantial portion of caregivers are adult children who are likely to have other responsibilities. Spousal caregivers may suffer from their own infirmities that may make it difficult to provide care to someone else. Equally important, our findings suggest that higher socioeconomic status of caregivers provides no assurance that they feel capable of caring for someone else.

ENDNOTES

- ¹ While the caregiver survey asks about the caregiver's knowledge, skill, and confidence for managing the health of the care recipient, the caregivers' responses indicate how able or competent they feel with regard to managing the health and health care of their care recipients (Professor Judith Hibbard, Personal Communication, November 2008).
- ² The Medical Expenditure Panel Survey (MEPS) is a federally sponsored survey of the U.S. civilian noninstitutionalized population. For more detailed information, see reference to MEPS in Chapter 1.
- ³ Other factors controlled for but not statistically significant included age, marital status, employment, insurance, number of admissions, number of office visits, need for assistance, paid help, and having had a medical error.
- ⁴ After we controlled for other factors (poor health, needing assistance, being male, and low PAM score), CTM score was no longer significantly associated with readmission. However, it appears that the CTM score is strongly related to the PAM score (described in the text), which could account for one variable's displacing the other. Thus, the relationship between CTM and PAM scores deserves further investigation.
- ⁵ Judith Hibbard, Personal Communication, November 2008.
- ⁶ To be included in the survey of people with chronic conditions, respondents were required to have one or more of the following doctor-diagnosed conditions: AIDS or HIV, arthritis (rheumatoid or osteoarthritis), cancer (any type), cardiac arrhythmia, chronic pain requiring prescription medication, cognitive impairment (dementia such as Alzheimer's), congestive heart failure, coronary artery disease, depression (or other mental health condition such as anxiety), diabetes (type I or II), serious respiratory condition (emphysema, chronic obstructive pulmonary disease, or asthma), epilepsy, hepatitis, high cholesterol, hypertension, joint replacement (hip or knee), lupus, Lyme disease, osteoporosis, other heart disease, Paget's disease, serious back problems (slipped or herniated disk), serious bowel problems (Crohn's disease or ulcerative colitis), or stroke. The list of chronic conditions used in the survey was derived from a list of chronic conditions referred to as the Clinical Classification System and developed by the Agency for Healthcare Research and Quality. See survey questionnaire for complete list of chronic conditions (*Beyond 50.09 Survey Report*).

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4

Chronic Care Delivery Needs to Change

Barriers to Good Care

Achieving Better Value for People
with Chronic Illness

Examples of Chronic Care Delivery



People with chronic conditions report many problems with their care, such as being readmitted to the hospital for the same illness, receiving the same medical tests from different providers because providers do not communicate with each other, seeking care in an emergency department when they cannot reach their own clinician, and, generally, experiencing lack of coordination among their health care providers. They also use more health care resources than other people. As we describe below, observers blame these problems on the organization of our health care system. Moreover, our health care system often does not provide ready access to the long-term services and supports that people with chronic illnesses often need.

“Barriers to improvements in care for people with chronic disease include the fragmentation of care delivery, poor transitions between and among settings, and misaligned payment incentives that fail to recognize the value of better integration of services.”

Experts in chronic care have articulated their vision of good care for people with chronic conditions, which we describe later in the chapter; however, how to implement that vision in ways that work best for the many types of patients across different delivery systems is not yet clear.

Some purchasers and health plans have tried a variety of approaches to improving care, with some success in improving outcomes and the efficiency with which care is delivered; these are described at the end of the chapter. But widespread, sustained improvements are unlikely until we address the barriers to good care.

BARRIERS TO GOOD CARE

Barriers to improvements in care for people with chronic disease include the fragmentation of care delivery, poor transitions between and among settings, and misaligned payment incentives that fail to recognize the value of better integration of services. Poor information systems make these problems worse because it is difficult for providers to track patients over time. Adherence to medications is a key component of effective chronic care management, and patients' failure (or inability) to take prescribed medicines is another major barrier to improvement.

In the first part of this chapter, we describe barriers and challenges.

PROVIDERS ARE NOT ORGANIZED TO SHARE INFORMATION AND CARE MANAGEMENT

Clinicians tend to focus on the particular problem that a patient presents at each visit. But delivering

good care for people with chronic diseases calls for proactive steps, by both individuals and providers, to care for chronic conditions between visits. For patients, this could include adhering to advice on exercise and diet, taking medications as prescribed, and monitoring signs and symptoms that could signal a downturn. For providers, it can involve making appointments and arranging transportation, as well as helping individuals and their caregivers gain access to a wide array of in-home and other services to help them function.

Health care is provided in many different settings—clinician offices, hospitals, post-acute care facilities, in the individual's house, and hospital outpatient and public health clinics. Health care is highly fragmented, and providers practicing in these different settings rarely have common electronic information systems or formal relationships. The health care system tends to be organized around the capabilities, scope of practice, and information systems of particular providers and institutions, even though patients cross the boundaries among them. Thus, people who visit multiple clinicians (which is the case for people with chronic conditions) too often have to literally carry copies of medical records and test and

imaging results from one clinician to another so that all clinicians participating in their care have up-to-date and complete information. Within these health care settings, whether they are hospitals, clinician offices, or nursing homes, care is generally organized around the providers, not patients. The Institute of Medicine's 2001 report *Crossing the Quality Chasm: A New Health System for the 21st Century* presented four areas where health care should be redesigned to organize care around patients' needs (Institute of Medicine [IOM], 2001):

- (1) care should be based on continuous health relationships;
- (2) care should be customized based on patient needs and preferences;
- (3) patients should be the source of control; and
- (4) knowledge should be shared and information should flow freely.

Another challenge is that many clinicians are very busy. Providing all recommended services and following guidelines for care of chronic conditions during patient visits would consume even more time out of their day. One clinician estimated that providing all recommended preventive and recommended disease control care would take 18 hours per

day, a figure that would not even include treating acute illnesses (Yarnall, 2005).

Most clinicians work in small, single-specialty practices, with few formal ties to the other providers that their chronically ill patients are likely to encounter. Clinicians' offices usually lack interdisciplinary teams and health information systems that can be effective in properly managing chronic illnesses and overseeing smooth transitions across care settings. Interdisciplinary team care brings providers from different disciplines together to care for the patient. Providers may include primary care physicians, registered nurses, social workers, physical therapists, pharmacists, occupational therapists, recreational therapists, dietitians, home care providers, personal care attendants, and drivers.

What barriers prevent the formation of interdisciplinary teams in modern health care? One is limited time: time for health professionals to get together to discuss patient care, and time for the family to meet with the team. Another barrier is communication (Penson, Kyriakou, Zuckerman, Chabner, & Lynch, 2006), which is exacerbated by the lack of time. Communication is critical to gather data and successfully implement

a treatment plan. Ideally, communication is coordinated by one person so that different clinicians do not have to ask the patient the same questions over and over. However, usual practice does not call for one person accountable for coordinating care. Communication remains one of the most important influences on the quality of care and can determine the nature of clinical outcomes (Boyle, Miller, & Forbes-Thompson, 2005).

Another barrier is the lack of educational preparation and training of health providers to work in teams and to understand the particular issues facing older adults. Some universities, for example Thomas Jefferson University in Philadelphia, have coordinated organized education across type of health provider, but examples of cross-disciplinary education programs are rare. Also rare is education or continuing education that develops competency in geriatric care. The Institute of Medicine recently recommended that health care professionals be required to demonstrate their competence in the care of older adults as a criterion of licensure and certification (IOM 2008).

A 2005 systematic review of quality improvement interventions for people with diabetes found that

assigning non-clinician staff to management roles improved health care outcomes the most for a group of people with chronic conditions (Heisler, 2008). Having a team was in itself not enough to improve care; a crucial element was allowing nurses or pharmacists to act independently to change medications without physician approval.

Other clinician practices have formed multispecialty group practices to provide care. These practices have more capital to invest in decision support tools, communicate more readily, and are more likely to support the interdisciplinary teams that are suited to manage chronic diseases. Despite generally high marks for enhanced patient outcomes, the large multispecialty group practice is atypical in many areas of the country.

HEALTH INFORMATION TECHNOLOGY TO SUPPORT CARE PROCESSES AND DECISION MAKING IS LACKING

Health information technology (HIT) holds promise for better delivery of chronic care and, eventually, cost containment. HIT can facilitate information exchange among providers by means of interoperable health records; provide decision support

for clinicians and patients; enhance clinician and patient communications with e-appointments and e-mail; and encourage patient self-management by providing online information on lab and other test results. HIT is a cornerstone of some state initiatives to improve chronic care (see Text Box 1) and is used widely in many European countries.

HIT also supports quality improvement by making data collection and reporting on quality measures easier, which in turn can help providers assess their performance and identify areas needing improvement. The same type of information can be made available to consumers who can use comparative information on performance to choose high-performing clinicians and hospitals.

However, HIT is not widespread. A recent survey found that only 4 percent of clinicians have adopted fully functional electronic medical records, and 13 percent have a basic system (DesRoches et al., 2008). The researchers defined a fully functional electronic medical record following the Institute of Medicine criteria: it would record patients' clinical and demographic data, allow providers to view and manage results of laboratory tests and imaging, manage prescription and other orders for ancillary services, and support clinical decisions, including warnings about drug interactions or contraindications.

The lack of common frameworks and standards for interoperability and connectivity among clinicians, hospitals, and other health care institutions and the cost of acquisition and adoption pose real barriers, particularly for providers in rural and underserved areas. One of the main deterrents to clinicians' adoption of HIT is that they do not perceive a return on their investment, which includes not only the cost of the software, but learning new systems and changing administrative processes. Further, clinicians do not typically share savings that may come from using HIT to improve care. Most often, such savings accrue to health plans and payers, not providers.

GOOD CARE DURING THE TRANSITIONS BETWEEN CARE SETTINGS IS LACKING

Many problems can arise during patient transfers from one health care setting to another—leading to gaps in care in which patients “fall through the cracks,” adverse outcomes that could have been prevented, and stresses on family caregivers. These problems include unnecessary duplication of services, inappropriate or conflicting

HIT: A TOOL TO IMPROVE CHRONIC CARE FOR DIABETES PATIENTS

Diabetes affects nearly 24 million people in the United States, and an additional 57 million people are believed to have pre-diabetes, a condition that puts people at increased risk for diabetes (U.S. Department of Health and Human Services [DHHS], 2008). Researchers estimate that 50 million Americans will suffer from the disease by 2050, costing the country \$351 billion annually in direct health and indirect societal costs (Rowley & Bezold, 2005).

In response to this challenge, some researchers have begun to develop programs to help improve diabetic patients' health outcomes. One example is the Vermedx Diabetes Information System (VDIS), a patented disease management program developed during a **five-year clinical trial** funded by the **National Institutes of Health**. This registry-based decision support and reminder system is based on the key principles of the Chronic Care Model, described later in this chapter.

(CONTINUED)

HIT: A TOOL TO IMPROVE CHRONIC CARE FOR DIABETES PATIENTS (CONTINUED)

The VDIS registry is populated automatically by electronically submitted test results from clinical laboratories. Using American Diabetes Association guidelines as a basis, results are reported back in five ways: (1) providers receive faxed flow sheets of test results and recommendations for further action after any new result, (2) patients receive letters recommending they discuss their diabetes care plan with their provider after reports of very elevated blood sugar or low-density lipoprotein cholesterol, (3) providers receive faxed reminders whenever a patient is overdue for a recommended test, (4) patients receive reminders by mail when they are overdue for testing, and (5) providers receive quarterly lists of all their diabetic patients sorted by the level of blood sugar control.

Participants are enrolled in the program but can choose to opt out of it. Patients receive a preliminary letter that notifies them that their clinician is participating in the program. The letter also states that their clinician believes that participation would be beneficial,

care recommendations, medication errors, lack of appropriate recommendations for follow-up care, inadequate patient and caregiver preparation for receiving care at the next health care setting, and conflicts over patient or family treatment preferences (Boockvar & Burack, 2007) (see Case Study). Poorly executed care transitions can also lead to greater use of hospital and emergency services and result in unwanted or unnecessary care, ultimately increasing health care costs (Coleman, Smith, Frank, Min, Parry, & Kramer, 2004; Tew, 2005).

Case Study. Lack of Continuity between Nursing Home and Hospital Care

An 88-year-old male nursing home resident with advanced dementia experiences a bout of chest pain. The patient was evaluated in the emergency room of a large urban hospital and, despite admonitions from his dementia specialist to temper aggressive care, was subjected to open heart surgery followed by insertion of a feeding tube to “get him over the hump.” On transfer to the nursing home, it was immediately clear to the patient’s newly acquired nursing home physician that his severe functional and cognitive impairment would not get better. The patient’s three sons quickly embraced the notion of a comfort-oriented approach, which included discontinuation of the feeding tube. The patient died comfortably a few days later with the family grateful for the care experienced in the nursing home but angry over the painful and unnecessary hospitalization. Preventing case scenarios such as this will require enhanced continuity and coordination of care between hospital and nursing home (adapted from Boockvar & Burack, 2007).

People with chronic conditions are especially vulnerable during care transitions. For example, someone with diabetes admitted to a hospital for an acute event, such as a heart attack, may not be in a position to explain what drugs he or she is taking. Therefore, providers must take care that any new treatments or medications they prescribe to address the acute condition do not make chronic conditions worse or have unsafe interactions with existing medications.

Older people with multiple complex chronic health conditions often need care in many settings with numerous care transitions. Some of them will have complicated transitions, or move from a less-intensive to a more-intensive care setting (e.g., home to hospital) (Kind, Smith, Frytak, & Finch, 2007). “A pattern of many complicated transitions within a short period of time can indicate health system failures; these patterns are promising targets for improved quality and coordination

of care” (Kind, Smith, Frytak, & Finch, 2007). Although intended to accommodate changes in patients’ care needs, these transfers frequently lead to communication errors; adverse events that could have been prevented; and patient, caregiver, and provider dissatisfaction (Boockvar & Burack, 2007).

Home to Hospital—People who move from home to the hospital often arrive without any medical or pharmacy records and are in no condition to give providers information about their medical histories (including their prescription drugs), and so providers operate in a vacuum. In such situations, providers often resort to ordering tests and procedures to diagnose conditions and stabilize patients. While this approach is aimed at trying to accurately diagnose and treat a sick patient, it often presents unnecessary health risks for the patient and drives up the cost of health care.

Hospital to Home—The return home after a hospital stay, especially a prolonged one, can be stressful for individuals and their families. Transitioning from an environment where all care needs are the responsibility of health care professionals to one where the recovering patient (or a family caregiver) is responsible for care can be physically, emotionally, and financially challenging. The challenges are even greater for patients (or family members) who either do not receive or do not understand discharge instructions, treatment plans, medication regimens, or follow-up instructions. Health providers do not always listen to patients or their caregivers or assess what they are willing and able to do to adhere to advice about follow-up care.

People with chronic conditions do not always have the information they need when they transfer from a hospital (emergency room or regular care) to another care setting. For example, Pennsylvania’s Patient Safety Authority found that among 800 discharge reports from hospitals submitted to the Authority from 2004 to 2007, 30 percent of patients did not receive verbal or written discharge instructions. Patients received incomplete medication instructions, incomplete prescriptions, or another patient’s prescription or instructions (Patient Safety Authority, 2008).

A study of patients ages 75 and older who were readmitted to the hospital emergency department less than a month after a previous discharge found incomplete documentation related to medication changes on two-thirds of all discharge documents. The study also found that hospital

but that patients are free to opt out. Patients who wish to withdraw are asked to call their provider or a toll-free number provided in the letter, and retain the right to do so at any time. Ten business days after mailing the letters, the system is turned on for all patients who do not opt out.

The system is used by a wide variety of clientele, including managed care organizations, hospital systems, and clinician practice groups. The system has also been used by the New York City Department of Health and the San Antonio Metropolitan Health Department to examine the scope and nature of the diabetes epidemic within their populations, and will likely be used as a foundation for future outreach programs.

Clinical trial results indicate that the VDIS improves treatment, significantly reduces patient treatment costs, and is viewed positively by both clinicians and patients (Vermedx 2008).

readmission was related to medication problems for nearly 40 percent of the patients involved, and that such problems were preventable for more than three-fifths of them (Witherington, Pirzada, & Avery, 2008).

Another study found that 78 percent of emergency room patients do not understand the care they received or their discharge instructions. Moreover, most patients appear unaware of their lack of understanding and report inappropriate confidence in their comprehension and recall (Engel et al., 2008).

Hospital to Post-Acute and Nursing Home Settings—After leaving the hospital, Medicare beneficiaries sometimes go on to post-acute settings (Liu, Gage, Harvell, Stevenson, & Brennan, 1999), such as a skilled nursing facility (SNF), home health agencies, or inpatient rehabilitation facilities (Johnson, Holthaus, Harvell, Coleman, Eilersten, & Kramer, 2001). A recent report to Congress by the Medicare Payment Advisory Commission found that between 2000 and 2005, Medicare patients who received post-acute care from SNFs risked receiving poor care. Specifically, the report found that growth in the rehospitalization rates for four conditions that can be prevented with good ambulatory care—congestive heart failure, urinary tract infection, sepsis, and electrolyte imbalance—averaged almost 9 percent per year (Medicare Payment Advisory Commission [MedPAC], 2008). Improved communication about the patient between the discharging hospital and the receiving SNF could improve outcomes for these patients.

Patients often go from hospitals to nursing homes without critical information about the care they received while hospitalized or new or continuing medications, or without post-hospital treatment plans. A recent survey of New York nursing home administrators found that over one-quarter of respondents reported that they did not receive all the information needed to provide adequate care for residents transferred to their facilities from hospitals. Fewer than half reported receiving readable and easily understood post-hospital care plans, and three out of five reported receiving information about the purpose of each prescribed medication. Fourteen percent of administrators also reported patient harm caused by inadequate communication of health information between the hospital and nursing home (Boockvar & Burack, 2007). These findings are consistent with previous reports of inadequate transfer of information between hospitals and nursing homes, and a growing recognition that lapses in communication and other care processes during patient handoffs can cause harm (Boockvar & Burack, 2007).

Post-Acute Setting to Home—Patients transitioning home from post-acute settings can experience many of the same problems that patients who return home from acute care settings do. Moving from an environment where intensive levels of rehabilitative services and other care needs are provided to the home environment where patients (or family members) are responsible for continuing care plans on their own can produce high levels of anxiety and may result in incomplete care or premature discontinuation of care.

Nursing Home to Hospital—Because nursing home residents are “disabled, tend to have multiple medical conditions, and live in an environment that predisposes them to acute institution-acquired illness” (Boockvar & Camargo, 2003), they often need inpatient hospital care. National studies have shown that 25 percent to 49 percent of nursing home residents are hospitalized each year (Boockvar & Camargo, 2003). Ideally, patients moving from the nursing home to the hospital setting would have their medical history, care plans, and treatment wishes sent along with them. However, this is not always the case. Without this important information, practitioners operate in a vacuum, often duplicating x-rays and laboratory tests in order to piece

together the acute condition responsible for the hospitalization, as well as to identify other possible underlying conditions. Many of these tests might have been avoided if the patient's information had been available to hospital personnel.

MANAGING USE OF PRESCRIPTION MEDICATIONS IS CHALLENGING

People with chronic illness typically take many prescription medicines. In 2004, for three chronic conditions, the average number of prescription medications filled that year was 26.5 (at a cost of \$1,853); for five or more chronic conditions, the average number of prescription medications was 57.1 (at a cost of \$3,799) (Anderson, 2007). While just over half of total expenses for adults' medical care in 2005 were for treatment of chronic conditions, almost three-fourths (72.9 percent) of all dollars spent on prescribed medicines were for treatment of chronic conditions (Machlin, Cohen, & Beauregard, 2008). Properly managing these medicines is an essential component of good management of chronic disease. While prescription drugs play a vital role in the treatment of chronic disease—they can prevent disability and early death—they also present a serious care management challenge. With multiple chronic conditions, the risks of problems due to interactions from multiple medications and supplements increases, often creating harmful and debilitating effects. Furthermore, as people age, their bodies are less able to metabolize medicines, putting them at even greater risk for complications.

Despite the potential life-saving properties of some medicines used to treat chronic conditions, they can also threaten older adults' well-being if not prescribed or used appropriately. Polypharmacy, which means “many drugs,” can result in problems if a person takes more medications than are actually needed. Even if one takes only one prescription medicine, the addition of an over-the-counter (or non-prescription) drug and a few dietary supplements may cause polypharmacy issues. When used alone, each drug may not cause any problems, but when used together, one's risk of experiencing drug-drug interactions, and other adverse drug events, increases exponentially (Rollason & Vogt, 2003)

Some prescribers, upon hearing of a patient's new symptoms that the patient thinks may be related to his or her current medicine(s), automatically reach for a prescription pad. This approach, which adds to the mix an additional drug to “treat” problems caused by the existing regimen, is called “prescribing cascading.” Unfortunately, polypharmacy problems due to cascading are common and can have serious adverse complications in older adults, but the root cause may go unrecognized by even highly skilled providers. For many older adults, decreasing—not increasing—the number of medicines used is a much safer approach, and can help isolate drug-related problems.

Some prescribers are unaware of drugs that are contraindicated in the elderly. The Beers list identifies 68 drugs that are potentially inappropriate in the elderly. Despite the availability of this resource, elderly individuals do take them.

The failure of people with chronic illness to follow their prescription drug regimens as prescribed is widespread, which often results in serious consequences for an individual's health and well-being. One recent study found that about half (52 percent) of persons ages 65 and older with three or more chronic conditions were not taking medicines as directed. Roughly a third (35 percent) of respondents cited cost as the reason for their non-

adherence. Among older, chronically ill people who skipped doses, stopped taking a drug due to side effects, or felt that they did not need to take a particular drug, only about a quarter (27 percent) talked with their clinicians about these issues (Wilson et al., 2007).

Patients, caregivers, and health care providers can take steps to improve care, but system and clinician barriers make this difficult. Barriers include lack of trust between clinician and patient, and, in some cases, providers' negative attitudes and inadequate knowledge about the disease and value of guideline-recommended care (Simpson, 2006). Successful interventions are often labor intensive, require hands-on involvement of a multidisciplinary team, and must be sustained over the duration of therapy.

Providers need to spend more time talking with patients about drug therapies and emphasizing the importance of adhering to them or discussing why they should be stopped. People with chronic illness and their caregivers need to be more proactive in managing care—keeping an up-to-date list of all medicines being used and sharing it with every health professional who writes prescriptions and with all pharmacists involved in a patient's care. A pharmacist might be able to recommend changes to simplify dosages, minimize side effects, eliminate duplicate medicines, and provide lower-cost options.

Persons with multiple chronic illnesses and functional limitations due to physical or cognitive impairments may need daily assistance with taking their medications. Such help is generally either provided by a family caregiver or home health aide.

PAYMENT SYSTEMS DO NOT REWARD BEST QUALITY

Fee-for-service (FFS) payment—the most common way clinicians are paid—pays for discrete services, regardless of quality or outcome of care. Providers have an incentive to offer services whether or not they are needed. There is no explicit relationship between how much clinicians earn and how patients fare. Similar payment incentives exist for hospitals: when a patient's condition deteriorates following a discharge and the patient is readmitted (i.e., there is an initial admission and then a subsequent admission to address the preventable condition), or when a patient develops a preventable condition (such as an infection) while in the hospital and requires additional care, hospitals are paid twice.¹ FFS also discourages providers from furnishing services that are not covered under the insurance plan (such as prevention and care coordination). Even if clinicians would like to furnish these services, they may have limited time in their day to do so (Yarnall, 2005).

If enrollees do not remain with a health plan for a long time, the health plan may be less willing to invest in programs that have a payoff over the long term. Researchers analyzed costs and benefits of chronic care programs at two top health plans and found that “the net return to health plans and providers of improved diabetes care is negative in the first few years and zero over a decade interval” (Beaulieu et al., 2006).

Medicare may be better able to take advantage of savings that may accrue from care coordination because once beneficiaries enter the program, Medicare keeps them for life. The high prevalence of chronic illnesses among the Medicare population provides many opportunities for improving the appropriateness, effectiveness, and efficiency of care. Yet most Medicare beneficiaries are in the traditional program. An increasing share of those

who are in Medicare Advantage plans are in the type of plans that are not integrated delivery systems, such as private fee-for-service plans and preferred provider organizations. Therefore, innovative ways for providers to improve care for chronic conditions will need to be developed in the context of a fee-for-service delivery system. Ideally, the payment method would reward health plans and providers for keeping patients healthy and helping people with chronic conditions or disabilities to maintain maximum function.

Paying fee-for-service for individual care coordination services (e.g., e-mail consultations, home visits, use of certain information technology) lets the payer know that the provider is performing the services. However, doing so would likely increase spending for those services by encouraging providers to furnish the services to many people. Creating some risk for outcomes—especially financial ones—would curb some of this potential, and creating risk for quality is likely to spur improvements in care. Incentives for patients can increase their motivation to adhere to advice and healthy behaviors. For example, most insurers offer a uniform benefit package with standard patient cost sharing that does not reflect differences in patients' conditions or responses to treatment or differences. A benefit design with lower cost sharing for medications that help treat a chronic disease could improve adherence.

Many integrated health plans or delivery systems give providers incentives to adopt programs that improve quality, reduce waste, and, potentially, contain costs. For example, in an integrated delivery system that is paid a monthly capitation from a plan or purchaser, the savings from lower hospital use could be shared with clinicians. Each payment approach has advantages and disadvantages. Fee-for-service encourages unnecessary care, while capitation can cause providers to cut back on needed care. Payment approaches that combine elements of both approaches are worth testing to explore whether providers act on incentives to achieve the outcomes we want: high value and high quality.

Health policy experts, including the Institute of Medicine, agree that changes to payment systems are needed to create the incentives for quality improvement. However, little innovation in this area is actually occurring (Tynan & Draper, 2008). A recent study found that most actual pilots of payment reforms for clinicians and hospitals are small scale and experimental. The authors cite four issues blocking the way of widespread adoption of payment reforms: fragmented care delivery, lack of payment for non-clinician providers and services that support chronic disease care, potential for revenue losses from the provider perspective, and lack of a champion for these reforms (Tynan & Draper, 2008).

DISPARITIES IN CARE AND LACK OF INSURANCE DETER ACCESS TO PRIMARY AND CHRONIC CARE

Racial and ethnic disparities in health are well documented (IOM, 2003; Mayberry et al., 1999). Although the challenges around effective chronic disease management exist for all people, some groups of the population have even more challenges because of higher prevalence of disease and because of a lack of continuous care due to lack of insurance coverage (see Text Box 2). In this section, we explore three areas where disparities can undermine effective chronic disease management: insurance status, having a usual place for receiving health care, and patient-provider communication.

THE OLDER POPULATION IS BECOMING MORE DIVERSE

The composition of the older population is expected to change, becoming more racially and ethnically diverse. In 2003, 83 percent of older adults were non-Hispanic white, 8 percent were non-Hispanic black, 6 percent were Hispanic, and 3 percent were Asian. By 2030, an estimated 72 percent of older Americans will be non-Hispanic white, 10 percent non-Hispanic black, 11 percent Hispanic, and 5 percent Asian (He, Signups, Volkoff, & DeBarros, 2005).

UNINSURED RATES ARE HIGHER AMONG MINORITY POPULATIONS

Persons who are uninsured have sporadic contact with the health care system (often through emergency rooms) risk having their conditions worsen before they receive any care, and are less likely to receive follow-up care. They are also 30 percent to 50 percent more likely to receive hospital care that may have been avoided if they had health insurance to pay for their outpatient care. The average cost of these avoidable hospital events has been estimated at \$3,300 in 2002 dollars (Hadley, 2002).

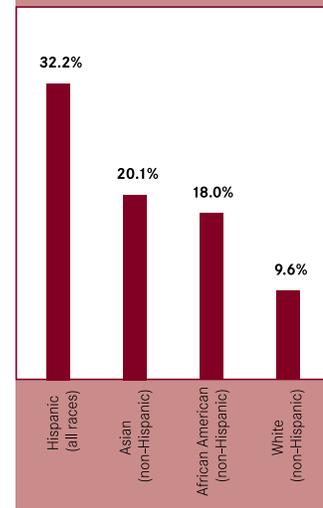
Persons with one or more chronic diseases who are uninsured often have a delayed diagnosis, resulting in poorer control of chronic conditions, worse health outcomes, and, ultimately, shorter life expectancy (Hadley, 2002).

Lack of insurance is more common among racial and ethnic minorities. Hispanics, African Americans, and Asians ages 50 to 64 are significantly more likely to be uninsured than their white counterparts (Figure 1). This is especially true for Hispanics, who are three times more likely than non-Hispanic whites to be uninsured.

HISPANICS ARE SIGNIFICANTLY LESS LIKELY TO HAVE A USUAL SOURCE OF CARE

Having a usual source of care or a regular health care provider makes it more likely that an individual will receive preventive services and other important health services, receive less care in emergency rooms, have fewer days in the hospital, and ultimately, realize improved health outcomes (DeVoe et al., 2003). An ongoing relationship with a provider is especially important for people who have one or more chronic illnesses because their conditions often require continuous monitoring and frequent changes in care regimens (DeVoe et al., 2003). A recent survey published by the Commonwealth Fund found that “when adults have health insurance coverage and a medical home—defined as a health care setting that provides patients with timely, well-organized care, and enhanced access to providers—racial and ethnic disparities in access

Figure 4.1
Lack of Health Insurance Is More Common among Minorities

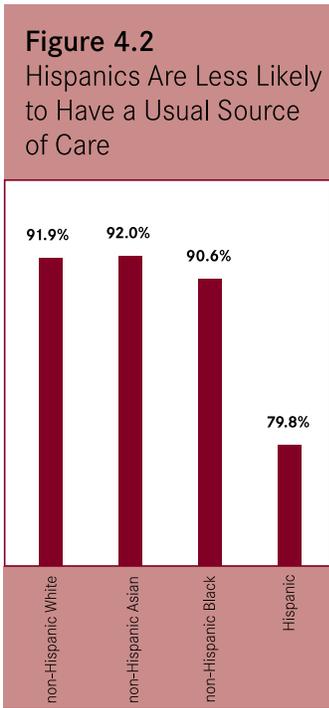


Source: AARP Public Policy Institute analysis of 2008 Current Population Survey.

Note: Data reflect adults ages 50 to 64 in 2007.

and quality are reduced or even eliminated.” The survey also found improved rates of health screening among those who have a regular source of care experience (Beal, Doty, Hernandez, Shea, & Davis, 2007).

Hispanics ages 50 and older are significantly less likely than non-Hispanic whites, Asians and African Americans to report not having a usual source of care (Figure 4.2). We see this pattern even after this population reaches Medicare age.



Source: AARP Public Policy Institute analysis of 2006 National Health Interview Survey.

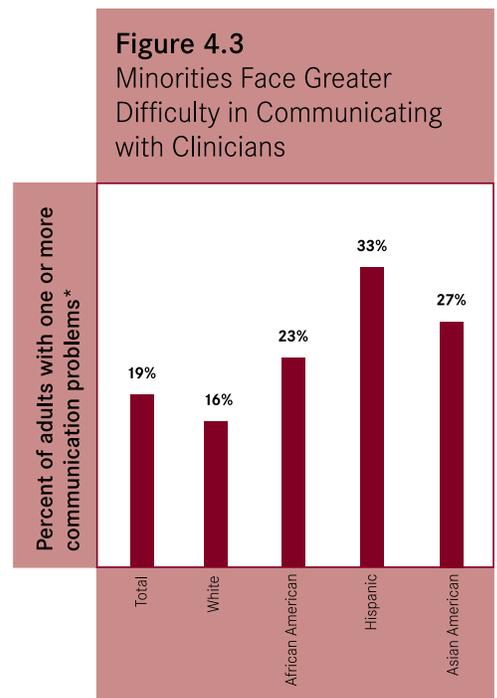
Note: Data reflect adults ages 50 to 64 in 2006.

MINORITIES ARE MORE LIKELY TO EXPERIENCE PROBLEMS COMMUNICATING WITH CLINICIANS

Effective clinician-patient communication is critical to the quality of care received by people living with chronic disease. It is unlikely that people who experience problems communicating with their providers are able to effectively navigate a complicated health system or successfully manage their chronic conditions. Health outcomes are jeopardized when people do not communicate effectively with their providers (see Chapter 2), do not feel comfortable communicating with their providers, perceive that their clinicians are not interested in or do not respect what they have to say, or are insensitive to their cultural needs and preferences (Jost, 2005).

A 2002 Commonwealth Fund survey found minorities experienced significant problems communicating with clinicians. African American (23 percent), Asian American (27 percent), and Hispanic (33 percent) respondents all reported having one or more problems with communication (clinician did not listen fully, patient did not understand fully, or

patient had questions but did not ask). In contrast, only 16 percent of white respondents reported these problems (Collins et al., 2002) (Figure 4.3).



Source: The Commonwealth Fund 2001 Health Care Quality Survey.

Note: Adults with health care visit in past two years.

*Problems include understanding doctor, feeling doctor listened, had questions but did not ask.

Minorities are also less likely to ask their health care providers questions. This is especially true for Asian Americans and Hispanics, who also report being less confident in their clinician, more likely to experience communication

problems with their clinician, less likely to understand everything their clinician tells them, and less likely to be involved in health decisions (Collins et al., 2002).

Poor provider-patient communication contributes to low compliance with care and medication regimens, dissatisfaction with health services, medical errors, and inefficient use of resources (Flores, 2006; IOM, 2003). Central to effective participation in the self-management of chronic illnesses is the ability to understand directions from providers on how best to manage care. Minorities—especially Asian Americans and Hispanics—are less able to understand care instructions given to them by their health care providers or prescription drug labels and so are more at risk for worse health outcomes (Collins et al., 2002).

Clearly, cultural and linguistic barriers play a role in these communication failures and create multiple opportunities for people to fall through the cracks in the health care system.

MINORITIES ARE LESS ENGAGED IN MANAGING THEIR CARE

Researchers have identified differences between African Americans and whites in their ability to participate in the

management of their health care and have suggested that racial and ethnic disparities in health care may be reduced by increasing patients' ability to participate in the management of their health care (Hibbard et al., 2008). A recent study focused on the extent to which increasing a person's "activation" (e.g., one's willingness and ability to play a role in managing one's care) may be an effective strategy for reducing racial and ethnic health care disparities. The findings suggest "that a focus on increasing activation holds potential for addressing racial and ethnic disparities in health" (Hibbard et al., 2008). Possible strategies for increasing activation include training people in how to ask their health providers questions, making changes to social environments that support healthy behaviors through worksite wellness programs, and developing community-based programs that help communities "engage and activate consumers" (Hibbard et al., 2008).

ACHIEVING BETTER VALUE FOR PEOPLE WITH CHRONIC ILLNESS

Important components of what is generally agreed to be good chronic care management are found in the Chronic Care Model (CCM) developed by Dr. Ed Wagner of the Group Health Cooperative of

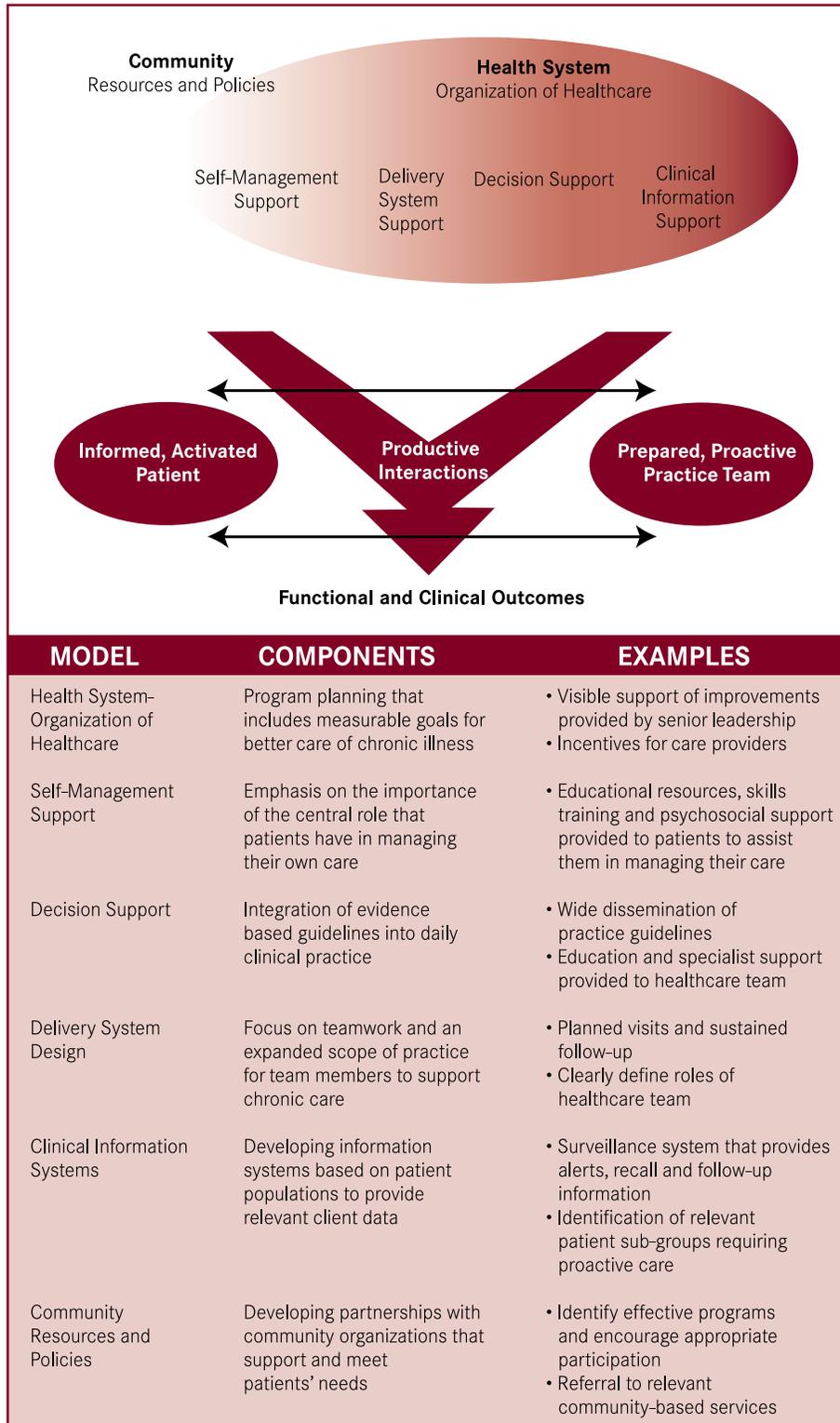
Puget Sound. The model contains six components: self-management support, community resources, organization of health care, interdisciplinary teams, decision support, and clinical information systems. Together, these elements go beyond today's often-restrictive acute care paradigm to improve patient care.

Self-management support is the component that most directly engages the individual. Self-management emphasizes building individuals' "confidence and skills in managing their condition" in order to "help patients to set limited goals for improving management of their illness, identify barriers to reaching their goals, and develop a plan to overcome the barriers" (Wagner, 2001).

Interdisciplinary teams are part of the CCM's call to delegate many care responsibilities from the clinician to others. Many of these functions do not require clinical training, and non-clinician team members on an interdisciplinary team could efficiently and consistently perform them.

Decision support means that care is guided by evidence-based guidelines that are "woven into the fabric of patient care." Decision support encompasses a number of activities including training of providers, a patient

Figure 4.4 The Chronic Care Model (Wagner et al., 1999)



registry that generates automatic reminders, flow sheets, and patient assessment tools. Ideally, it also encompasses close relationships with medical specialists.

Clinical information systems must include, at minimum, a patient registry tracking each patient with a chronic condition and prompting the team to take appropriate actions. Ideally, it should also include electronic patient records and generate statistics that allow the clinicians and team members to evaluate their performance.

Another component is “patient-oriented *community resources* [that] help to activate and inform patients and families to better support and cope with the challenges of living with and treating chronic illness.” This encompasses such activities as nutrition counseling and peer-support groups.

The *organization of health care* is the foundation of CCM and is particularly challenging. Outside of an integrated delivery system, a strong clinician commitment to reorganizing care is required. Dr. Wagner found, in conducting workshops to teach the CCM to provider organizations, that “the visible support and promotion of the chronic disease improvement project by organization leaders was a major predictor of success.”

Payers and plans have tested myriad programs that take elements of the CCM to improve the care of people with different chronic conditions. These have been tried by Medicare, Medicaid, the Department of Veterans Affairs, and private plans. We provide a sampling of these programs to illustrate the range of potential delivery options.

Even though some researchers have looked across these programs to identify successful elements, we still lack evidence on what works and for what patients and in what kind of a delivery system. A lack of clinical practice guidelines based on evidence for many conditions and condition combinations also complicates our assessment of which programs work best.

Coordination with long-term services and supports: A missing piece in chronic care? Because of the close interrelationship between chronic illnesses and functional limitations that can result in disability, older persons often need not only a limited number of “post-acute” home health visits but ongoing assistance with personal care in order manage their health conditions and remain independent. The need for essential services as help with eating or bathing and other daily activities, which are not covered

by medical insurance, is often not assessed or well coordinated with chronic care delivery. Because such services, which are primarily funded by Medicaid, are themselves fragmented at the state level, their assessment, coordination and management require additional time and effort. In the absence of coordinated care management by professionals, such responsibilities typically fall to family and other informal caregivers.

EXAMPLES OF CHRONIC CARE DELIVERY

Transitional care programs aim to improve the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location (American Geriatrics Society [AGS], 2002). Program elements typically include a comprehensive plan of care and practitioners with training in chronic care management who have current information about the patient’s goals, preferences, and clinical status. Transitional care programs address logistical arrangements, patient and family education, and coordination among the health professionals involved in the patient’s transition from one setting to another. Transitional care, which encompasses both the *sending* and the *receiving* aspects of the transfer,

is essential for persons with complex care needs (AGS, 2002).

Preparing individuals and family members for care transitions is an important component of improving the quality and outcomes of care for older persons with chronic illness. Such preparation encourages increased buy-in to the plan of care by individuals and their families, decreases anxiety, and supports patient involvement. Communication among providers is also critical. One promising model funded by the Hartford Foundation and based at the University of Colorado is called the *Care Transitions Intervention*. This program provides individuals and their caregivers with tools and support to encourage them to participate more actively in their care transitions.

Another example of a transitions program is the Transitional Care Model (TCM). This model has been explored in a series of three randomized clinical trials funded by the National Institute of Nursing Research (<http://www.nursing.upenn.edu/centers/hcgne/TransitionalCare.htm>). Dr. Mary Naylor and her research team have built this model of transitional care delivered by master’s-prepared advanced practice nurses with physician backup. The model targets older adults with no

cognitive impairment who have two or more risk factors, such as poor self-health ratings, multiple chronic conditions, or a history of recent hospitalizations. The heart of the model is the master's-prepared advanced practice transitional care nurse who is well versed in national standards of care delivery and experienced in providing comprehensive care and acute and community-based services (Naylor, 2006).

The transitional care nurse monitors and manages transitions across settings (e.g., acute to community) and health status for an average of 18 patients to improve patient care and outcomes. The nurse helps patients and caregivers understand and process information, manage health issues to prevent decline, and reconcile and manage medication, and is an advocate for the patient. Making home visits to patients is an essential component of TCM as it provides the transitional care nurse the opportunity to assess and monitor the patient and home environment and provides the opportunity to educate and make recommendations to the patient and family/caregiver(s).

Disease management programs focus on engaging and educating the patient in his or her own care and providing advice and counsel between clinician visits. These programs tend to focus on a single disease. Disease management programs are intended to help individuals with day-to-day management of chronic conditions in their asymptomatic or non-acute phases, for example, by providing support for adhering to medical advice, including taking maintenance medications and making behavioral changes. For some conditions, periodic visits to a clinician may be sufficient. But for others, continual oversight by professionals and a high level of engagement by the patient are warranted. Many of these programs are operated by vendors who contract with a health plan or employer to provide the service.

One example of a disease management program is the one offered by the Indiana Medicaid program. The program worked with contracted entities to run a chronic disease management program for its enrollees with congestive heart failure or diabetes. It developed two types of interventions: for high-risk patients, the program furnished an intensive nurse care management program; for low-risk patients, the intervention was periodic telephone calls. The more intensive intervention involved using registered nurses to supervise care managers, who reviewed medical records, visited enrollees at home, and provided follow-up by telephone. These care managers provided resource materials, referred patients to

THE FOUR COMPONENTS OF THE CARE TRANSITIONS INTERVENTION:

- A patient-centered record that consists of the essential care elements for facilitating productive interdisciplinary communication during the care transition (referred to as the Personal Health Record, or PHR).
- A structured checklist (Discharge Preparation Checklist) of critical activities designed to empower patients before discharge from the hospital or nursing facility.
- A patient self-activation and management session with a transition coach (geriatric nurse practitioner) in the hospital designed to help individuals and their caregivers understand and apply the first two elements and assert their role in managing transitions.
- Transition Coach follow-up visits in the skilled nursing facility (SNF) and/or the home and accompanying phone calls designed to sustain the first three components and provide continuity across the transition.

Source: http://www.caretransitions.org/intervention_design.asp.

community resources, and helped provide communication with clinicians (Holmes, Ackermann, Zillich, Katz, Downs, & Inui, 2008).

Case management programs tend to go beyond disease management to provide a more intensive set of services to complex patients who often have multiple chronic illnesses and experience acute episodes. Typically they are targeted to the patients with the most complex and serious needs. One example of a case management program is offered by the Department of Veterans Affairs (DVA) through its Home-Based Primary Care (HBPC) program, which provides care through a multidisciplinary team in the patient's home after discharge from a hospital. The program is for homebound veterans or for those whose care needs will best be met at home (DVA, 2008). The program has several key elements. It screens patients to find those who are at highest risk and targets care to them, designates a care manager within a multidisciplinary team, provides 24-hour contact, requires prior approval for hospital care, and involves the team in any hospital admission planning. Specific services include teaching, management and administration of medication, wound, pain, and medical management, laboratory draws, tele-home care, and care coordination between DVA and community care providers (DVA, 2008).

Medical or health care homes offer a patient coordinated care through a primary care clinician who tracks, monitors, and oversees the patient care over time. They use a patient-centered approach to improving care coordination, with a clinician or clinical practice assuming responsibility for coordinating, integrating, and enhancing access to needed services, including approaches to improve patients' confidence and knowledge in managing their condition. Most proponents view the medical or health care home as a primary provider (which could include an advance practice nurse) whom patients choose as their main source of routine care; this primary provider then coordinates care from other providers, assures that patients receive good preventive care, and directs patients to care across settings. Generally, medical or health care homes demonstrate that they meet certain standards and thereby qualify to receive monthly fees from the payer who is sponsoring the program for their patients in addition to normal fee-for-service payments. Some clinicians have set up medical or health care homes independently from health plans, charging patients additional fees to use their services.

In most models, the primary provider is the patient's primary care clinician, such as an internist, geriatrician, or nurse practitioner. In some cases, the primary provider may be a specialist for patients with known chronic conditions, such as an oncologist for a cancer patient, who may benefit from regular visits to a specialist. Medical or health care home models are often based on an interdisciplinary team approach including a variety of supporting health care professionals, such as a nurse, pharmacist, therapist, nutritionist, medical social worker, and medical assistant, depending on the needs of the patient.

Medical or health care homes, because they provide care coordination, are a promising model for patients with chronic conditions. Most medical or health care home models incorporate the following features:

- Patients' voluntary choice of a primary provider or medical practice
- Easy access and communication, including after business hours
- Periodic assessment of a patient's clinical needs based on evidence-based protocols when available, and assessment of social and support needs and resources of patient and family caregivers, as needed

- Care management, often employing an interdisciplinary team approach, especially for patients with multiple chronic conditions
- Education and training for patients and their family caregivers to support patient's ability to manage their condition
- Use of data to identify patients with specified conditions and risk factors, compile patient registries, track referrals and test results, and follow up with other providers, including community resources (preferred approaches rely on health information technology, such as interoperable electronic medical records and electronic prescribing)
- Collection of data to report standardized performance measures on cost and quality of care (AARP, 2007).

Medical or health care home projects are generating interest among payers. Successful examples of medical or health care homes include one sponsored by North Carolina Medicaid and one sponsored by Blue Cross Blue Shield of North Dakota. A demonstration project in Medicare will start in 2010.

Workplace health management programs not only help employees manage chronic conditions using strategies like disease management, they also try to help employees adopt healthy behaviors to prevent chronic disease. A Citibank program offers services that include consumer health education; preventive screenings and immunizations; behavior change, fitness, and work conditioning programs; and targeted interventions for those at risk or who have chronic medical conditions. Other program elements include *Taking Care*, a consumer health education newsletter, mammography screenings, and onsite fitness centers (C. Everett Koop Awards, 2008).

Comprehensive geriatric assessment is a set of services, often provided in a hospital geriatric unit, but also in outpatient settings, that relies on identifying all of a patient's health conditions and then developing and implementing treatment plans. The focus of these programs thus tends not to be on a particular chronic condition, but rather on a more global assessment of all the patient's conditions, including functional and psychological status. The programs rely on interdisciplinary teams to conduct the assessment and develop the treatment plan, which the team then communicates to the primary care clinician (Weiland & Hirth, 2004).

Patient navigation programs combine aspects of disease management programs with community and culturally sensitive care coordination. These programs have reduced racial, ethnic, and income-related disparities in the diagnosis and treatment of breast cancer using navigators and directors to help people access care (Vargas et al., 2008). Navigators are from the same community or culture as the patient and know the patient's care plans. Directors, who have administrative responsibilities in the delivery system, communicate regularly and openly with navigators to help remove barriers to care.

Nursing home-based models provide additional care and care coordination to residents of nursing homes. One such program, Evercare, primarily relies on nurse practitioners to monitor enrolled patients regularly and work with their clinicians to intervene quickly if issues arise (Kane et al., 2004). The program also pays clinicians for services not usually reimbursed by Medicare. The nurse practitioner works with nursing home staff to train

nursing home aides on providing good observations and better care. The nurse practitioner also works with residents' families.

Integrated acute and long-term care programs. Frail older persons often need not only acute and chronic medical care but also services and supports not defined as “medically necessary” by insurers, including

“Preparing individuals and family members for care transitions is an important component of improving the quality and outcomes of care for older persons with chronic illness.”

personal care, adult day care, home care, and transportation services. The Program of All-Inclusive Care for the Elderly (PACE) is a perhaps the best example of the integration of medical and long-term services and supports. The model also serves as a “health care home” for enrollees, a primary site where health care is coordinated. By combining payments from Medicare, Medicaid and private pay sources (for persons not eligible for Medicaid) into one capitated payment, the program permits delivery of a wide range of services that otherwise might not be covered (Hansen, 2008). In the PACE model, interdisciplinary teams provide primary care and other medical and long-term services and supports to participants with an average age of 80 who must meet the criteria for nursing home admission. Evaluations of the program have demonstrated improved quality of life, functional status, and more days in the community than in nursing homes for participants. The program, for which the prototype was On Lok Senior Health Services that began in San Francisco in the early

1970s, today is available in 22 states and will expand to an additional 27 states by the end of 2008 with the addition of many new sites in rural areas (Hansen, 2008).

Pharmacy care models use pharmacists to provide advice to older patients either directly or as part of interdisciplinary teams. A two-year study of 200 patients ages 65 or older using at least four medications for high blood pressure and high cholesterol was conducted at Walter Reed Army Medical Center in Washington, DC (Lee, Grace, & Taylor, 2006). For six months, patients received interventions that included medication education, regular follow-up by pharmacists including face-to-face consultations, and medications dispensed in time-specific packs. Then, for six more months, patients received either the continued interventions, or usual care (no special interventions). The study found much better adherence to prescribed medicines among participants who received the intervention.

The health plan Preferred Care implemented another example of the pharmacy care model. Specially trained pharmacists employed by the Wegmans grocery store chain in Rochester, NY, conducted Medicine Bag Reviews. More than 1,300 persons ages 65 and older who were taking four or more prescription

medicines received free in-person reviews of their medications. The pharmacists who conducted the medicine reviews had received training in geriatric pharmacology. Further, local emergency medical technicians (EMTs) had ready access to each person's medication list (and other identifying information) via a "Vial for Life" that was kept in the refrigerators of elderly members who had had a medicine review.

Members completed an intake form, including their typical diet; and were told in advance to bring their medication list, or their actual medications. The review included an evaluation of potential drug-drug interactions and checks for appropriate dosing; answering members' drug-related questions; and providing information on generic alternatives. Following the review, members received a one-page written summary of key conclusions to take home; a copy of the completed intake form was sent to the patients' home and to their primary care clinician. If pharmacists identified a contraindication, a Preferred Care staff member would contact the prescribing clinician within 24 hours. The study found 26 percent of participants had potential adverse drug interactions identified; medication adherence was 92 to 94 percent, almost twice

the usual rate of compliance; and falls dropped 35 to 40 percent (Agency for Healthcare Research and Quality [AHRQ], 2008).

CONCLUSION

The promise of improving the care of patients with chronic conditions while reducing costs has led the Congress and the Centers for Medicare & Medicaid Services (CMS) to test care coordination and disease management models in several demonstration programs for Medicare beneficiaries. To date these demonstrations have not found significant improvements in quality or reductions in spending; however, several demonstrations are still ongoing. The results of these demonstrations will provide important information for understanding when and how care coordination can enhance care for beneficiaries and whether the promise of reduced spending can be realized.

Published studies that have assessed care coordination have often been limited in scope and design. Study methodologies often raise more questions than they answer or have not been subjected to peer review. Many published studies have been about the effect of these programs on younger populations, which may not be applicable to older populations with many chronic conditions.

Recent reports from CMS contractors on demonstrations have focused on global measures of performance rather than isolating the features of programs that have worked and the populations for which they have worked best.²

More work is still needed before we understand what combination of tools has the best result for certain types of patients and health care problems. Many models have only been tested for one or two conditions, and we need to know more about whether models are likely to be transferable to other conditions and for patients with multiple conditions. Is a model that works for diabetes likely to work for congestive heart failure (CHF)? Is a model that works for asthma likely to work for chronic obstructive pulmonary disease (COPD)? Might models that have proved successful for one condition (e.g., diabetes) be useful for multiple conditions? Are there constellations of conditions that might lend themselves to particular approaches? For instance, are approaches that work for CHF likely to work for multiple conditions related to chronic cardiovascular conditions? Similarly, might approaches that seem to work for arthritis be likely to work for other chronic bone conditions? And what strategies work best for patients with cognitive impairments?

Another important area where we need more information is how to adapt success stories from carefully controlled studies often tested in organized delivery systems like health plans or the DVA, to our much larger, unmanaged fee-for-service delivery system. Changes in the incentives and the organization of care are needed to support sustained improvements to care for chronic conditions.

ENDNOTES

- ¹ Some payers are now experimenting with payment changes that attempt to recognize preventable complications acquired during hospitalizations and withhold payment in such situations.
- ² The Robert Wood Johnson Foundation's Health Care Financing and Organization program has just commissioned a study that will take a more detailed look at these programs, but the results are not yet ready.

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5

Conclusions and Policy Recommendations

Better Knowledge

Better Tools

Better Incentives



Chronic illness is rising among people ages 50+, and with age come multiple chronic conditions. These conditions can have a profound effect on people's lives, increasing their use of health care services and eventually leading to serious consequences, such as disability and death. People with chronic conditions and their family caregivers describe many challenges in managing the condition, and some of them point to shortcomings in the health care and social support system that make coping with chronic conditions even harder.

A serious problem for people with chronic illness is the loss of critical information as patients transition among settings, such as hospitals and emergency rooms. These settings are not organized around patients and their needs, but instead according to long-standing institutional practices. Care coordination requires that patients with chronic conditions understand their role in self-care and medication management, and that their preferences be incorporated into the care plan. Patients and caregivers should know whom to contact if individuals develop new symptoms or their condition worsens.

“Changes in the delivery of health care are needed to better support people with chronic conditions.”

Our survey finds that during transitions from health care facilities to other settings, some patients need more support than others. Patients at high risk for a poor transition include those with more than five chronic conditions, numerous office visits, poor health status, limitations on daily activities, need for assistance with patient care coordination activities, and a low level of engagement in their care.

The numbers of people with chronic illness grow each year, and people 50+ are more likely to have these conditions than younger people. In part, these conditions have become more visible because we have more ways to treat them; however, a sedentary lifestyle and poor diet are contributing

factors. Further, with improved treatment of acute conditions, we are leading longer lives—and the longer we live the more likely we are to experience these conditions. Indeed, older Americans are more likely to have multiple chronic diseases. Side effects and harmful drug interactions also increase with multiple medications for multiple conditions. For healthier people, chronic disease can be manageable, and people can take a primary role in taking care of their conditions. For people with multiple chronic conditions, the “oldest old,” and those approaching the end of life, the challenge is greater, and both these people and their caregivers need more support. Many studies have shown that important clinical information needs to flow among care settings, among providers, and to the patient and any caregivers.

Changes in the delivery of health care are needed to better support people with chronic conditions. Barriers to improvements in care for people with chronic disease include the fragmentation of care delivery, poor transitions among settings, and misaligned payment incentives that fail to value better integration of services. Poor information systems make these problems worse because it is difficult for providers to track patients over time. Medications are a key component of effective

chronic care management—taking medications can slow the progression of many conditions, but multiple medications can interact and create dangerous side effects.

RECOMMENDATIONS

Experts agree there are large gaps in the quality and delivery of health care for people with chronic illness. An important goal is to improve the care and quality of life for people with chronic disease and those who care for them.

Ideally, our extensive review of the issues around chronic care would lead us to recommend specific models of care, interventions, and financing that both improve the patient’s care and experience and reduce spending. However, while purchasers and plans are trying approaches that have had some promising results, the evidence is inconclusive about what will work in all circumstances, although the recommendations that follow point to program elements for which there is consensus.

Even though we know what good care for chronic conditions should look like, widespread, sustained improvements are unlikely until we address the barriers to good care discussed in the previous chapter. Addressing these barriers requires a multi-pronged strategy that includes better knowledge,

better tools, and better incentives. For each of these strategies, our recommendations are for changes aimed at providers, family caregivers, and patients—who play a critical role in managing their own care.

BETTER KNOWLEDGE

Expand testing of care delivery models to find out what works.

Recognizing the need for better care delivery for patients with chronic conditions, the Centers for Medicare & Medicaid Services (CMS) has sponsored many demonstrations of programs with differing features and differing target populations. The goal of these programs is to figure out what improvements in the delivery of care will enhance the patient’s experience and clinical outcomes. Other purchasers, including the Department of Veterans Affairs, Medicaid programs, and employers and health plans, also have experience with chronic care coordination programs, case management programs, and disease management programs. The medical home concept (called “health care home” in some states) is catching on among private and public payers at the state and federal levels. For example, CMS is piloting a medical home model in Medicare for coordinating care, with provider recruitment in 2009 and payment for services starting in

2010. A program using multispecialty physician group practices as the locus for chronic care management is still in progress.

To date, some of the programs have improved outcomes, though cost containment has been less consistent. More information is needed to identify the elements of programs that work best and how to target the right interventions to the patients who will benefit most so that resources are used most effectively. Different strategies may work for different patients; strategies could target people with different types of diseases, constellations and progression of disease, and abilities to actively manage disease. Once information is available on what elements of programs work best, it should be disseminated to all payers and providers. A national clearinghouse for information on chronic care and care coordination might be a useful way to learn from the many experiments by private payers, Medicare and Medicaid, and the Department of Veterans Affairs.

Although no one model or set of models is definitive in providing the best approach for all patients, some specific interventions are widely viewed as effective, such as a discharge checklist for patients leaving a health care facility. Health care facilities should use this list as part of their discharge procedure and share it with patients and caregivers to improve their preparation and understanding of what they should expect as they leave the hospital. Discharge information should go to the patient's primary provider, along with medical records from the admission.

Include best practices from chronic disease care in clinical preparation and training. As we learn more about what works in care for chronic conditions, educators should incorporate those findings into curricula for physicians, nurses, pharmacists, social workers, and other health care professionals. For example, multidisciplinary teams appear to be a feature of successful programs; this suggests using a model of team practice to educate and train students so they are prepared to practice in teams. The Institute of Medicine recently called for development of interdisciplinary teams in its report on building the health care workforce.

Today's health care workforce lacks key competencies needed to work in interdisciplinary teams. New multidisciplinary collaborations will be needed to provide patient-centered care (Sievers & Wolf, 2006). Another needed competency will be the use of quality improvement skills to reduce errors. Over the coming decade, health care and education for the health professions will be called upon to change dramatically. Medicare is one potential change agent, as it explicitly funds medical education.

Clinical education calls for interdisciplinary experiences, rather than education isolated in individual silos. Health care professionals will need to learn to lead interdisciplinary teams and implement evidence-based practices (Benedict, Robinson, & Holder, 2006). Providers will need to be trained to work in interdisciplinary teams, and financing and delivery systems should support this interdisciplinary approach.

Providers in practice also need to continue their education and learn from best practices in chronic care. Maintenance of certification programs and continuing education should include demonstration of competency in the care of older adults, family caregiver support, and new multidisciplinary chronic care

management approaches. These programs can disseminate findings to encourage providers to adopt innovations that improve care. Specialty societies can incorporate into practice guidelines the most effective practices in the management and coordination of care for chronic conditions.

Engage patients by giving them information they will understand and act on. One of the salient features of chronic disease care is that some patients and their caregivers can take steps to participate in their own care. For example, lifestyle choices like diet and exercise can help a diabetic avoid acute manifestations of the disease, and taking blood pressure medications regularly can keep hypertension under control. Recognizing and acting on warning signs and symptoms can avoid the need for emergency care later. Not all patients are able or willing to become effective managers of their own care owing to dementias or functional limitations, but many are.

Support family caregivers and engage them as partners with professionals. Family caregivers not only provide the vast majority of long-term services and support (LTSS) in the United States but also provide many health care services. And by default, they often serve as “care coordinators” of chronic health and LTSS services. Caregivers need information and skills to help them provide safe and appropriate health care and LTSS to care recipients; backup support, including respite; and assessment of their own needs and health risks. New models of “family-centered” care are beginning to emerge, in which nurses and social workers actively collaborate to improve support for family caregivers and work in partnership with them to improve quality (*American Journal of Nursing*, 2008).

Encourage wise use of pharmaceuticals in managing chronic conditions. Virtually all older adults seeking care for chronic conditions have prescriptions for medicines that help alleviate symptoms and maintain quality of life. Appropriate medication use is an essential part of slowing the progression of illness and avoiding side effects. Prescribers who care for people with many chronic conditions should take care to sort out all the medications to avoid harmful interactions. The dosages should be checked regularly, as people’s metabolism can change over time.

Once the optimal set of medications is found, clinicians should encourage patients to take them regularly by educating the patient and caregiver, using reminder systems, and tracking use over time. Counseling, reinforced with clear, written instructions, helps the patient understand the value of the medications. Affordable prescriptions are also critical to encouraging patients to use these therapies.

Several practices and activities would improve information flow among patients, providers, and prescribers.

- Providers should fully inform patients about the purpose of each medicine, its effects, and side effects. Availability of lower-cost alternatives and the potential for drug interactions should also be part of the conversation.
- Patients or caregivers should keep an up-to-date personal medication list that includes a record of all the patient’s prescriptions, nonprescription medications, and dietary supplements. Sharing such a list is especially important when patients transition among sites of care, but it is also important when multiple prescribers are involved in the patient’s care.
- Patients and caregivers should follow up on any required laboratory work that gauges how a medicine is working.

- Patients should consider medication therapy management programs and drug reviews, which all Medicare plans offer to targeted patients with high drug costs. Some health plans and pharmacists also offer these services.

Improve research on disparities and dissemination of information in this area. As we discussed earlier in this report, minority populations suffer more from chronic disease, yet their quality of care is worse. As we take steps to improve chronic care generally, it is important to focus on strategies to narrow the gaps in prevalence and outcomes among populations. Measuring disparities in health care is integral to comprehensive performance improvement. A consistent and uniform method of collecting information on an individual's race and ethnicity, gender, age, socioeconomic status, and primary language is a fundamental tool to address gaps in care (Agency for Healthcare Research and Quality [AHRQ], 2006). The next steps are to identify where to focus the most attention and resources and learn how to close the gaps.

BETTER TOOLS

Increase use of health information technology. A key element to better coordination of care—in particular for chronic disease, whose care takes place over a long span of time, through many providers, and across multiple settings—is health information technology (HIT). HIT can fundamentally improve care, save lives, reduce errors (e.g., through e-prescribing), and conserve scarce resources across all health care settings. Electronic decision support, in the form of reminders, can help clinicians follow evidence-based guidelines that can warn of contraindications, reduce errors and duplicative services, enhance care coordination, and improve patient-provider communications. Information systems also permit the development of disease registries within health care practices, which most experts agree are essential for monitoring the care and status of patients with chronic disease and in helping providers communicate with each other.

Develop better tools for patients to manage their conditions. People with chronic illness should have information and training to help them manage their own disease. Good communication with and among providers is just the beginning, but it is a critical component. In addition, better communication between providers and family caregivers is essential, as are better tools and resources for caregivers. Some chronic care management programs organize meetings among people with the same health care condition to share information and provide motivation and support for maintaining healthy behaviors. Also important is offering patients and their caregivers access to and information about community resources, including LTSS that will help them maintain function and independence. Chronic disease management programs should focus on communication with patients and their families and provide them with information about community resources.

BETTER INCENTIVES

Make innovative changes to payment policy. A strategy to improve health delivery must include changes in reimbursement incentives if behavior is to change. As discussed earlier in this report, most payment approaches encourage the use of services over improving long-term outcomes. Payment systems that reward good chronic care would be better keyed to outcomes, including patient experience, and encourage ongoing management of the disease to improve care and reduce preventable emergency room visits and hospital care. The incentives should prompt providers to work together toward the same goals and reduce duplication.

Financial incentives (e.g., “pay-for-performance” plans) can foster the delivery of high-quality, cost-effective care. Innovative payment methods to promote better coordination of care should address incentives to provide care that results in the best outcomes and discourage perverse financial incentives that are barriers to improved care coordination, such as additional payments for preventable hospital readmissions. Innovations in payment for episodes of care, including for chronic conditions, should be tested. However, these programs should be designed to ensure that they do not create barriers to care or lead to reduced service. Competitive bidding for coordinated care services also is worth testing. Medicare and Medicaid should join funding streams to help bring together health and long-term care for beneficiaries enrolled in both programs, if patient protections are included.

We support expansion and adoption of tested models that work well in certain areas, such as transition from hospitals (http://www.caretransitions.org/intervention_design.asp, <http://www.nursing.upenn.edu/centers/hcgne/TransitionalCare.htm>). We also support rapid testing, expansion, and adoption of medical home (or health care home) models led by clinicians, including advanced practice nurses, which promise to be effective for improving care of beneficiaries, particularly those with chronic conditions, and increasing efficiency in the health care system. Care coordination programs, including medical/health care homes, should test the use of positive incentives to encourage patient and caregiver participation.

Some individuals with chronic conditions need both medical and non-medical services. People finishing their Medicare home health benefit would benefit from improved coverage for physical and other therapies to help them maintain function and independence. Another valuable benefit would be expanded respite services for family caregivers.

Maximize use of the health care workforce. A common feature in many chronic disease management programs is to use nurses and other providers to lead a team that helps patients and their families manage their care and navigate the health care system. Primary care outcomes in patients treated by nurse practitioners or physicians have comparable outcomes when the nurses have the same authority, responsibilities, productivity, administrative requirements, and patient population as physicians (Mundinger, 2000). Laws and regulations often inhibit the ability of health professionals to practice at the highest level of their licenses.

Professional licensing laws should allow nurses, nurse practitioners, and other qualified health professionals to perform duties for which they have been educated and trained. Broadening the pool of clinicians may expand access to primary care and providers who can care for patients with chronic illness, especially in light of the coming shortage of primary care providers.

Make medications and preventive care affordable. Difficulty affording medicines is a common deterrent to initial filling and subsequent refilling of prescriptions, and this becomes an even bigger problem when the patient takes multiple medications. More than one-third (35 percent) of persons ages 65 years and older with three or more chronic conditions say they do not take some or all of their medications because they are too expensive. This can result in serious medical complications that may require additional medical visits, emergency room visits, hospitalizations, or nursing home admissions. The wide availability of generics can make drug therapy more affordable; however, generics are not available for all drugs, particularly expensive biologics.

People with chronic conditions should receive recommended preventive care and screening. Access to preventive and screening care should be convenient and free of charge to patients, particularly those with chronic conditions, since it can dramatically increase use of these services.

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