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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.

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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).

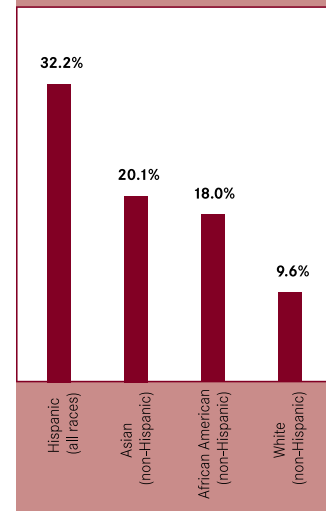
Persons with one or more chronic diseases who are uninsured often have a delayed diagnosis, resulting in poorer control of chronic conditions, worse health outcomes, and, ultimately, shorter life expectancy (Hadley, 2002).

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

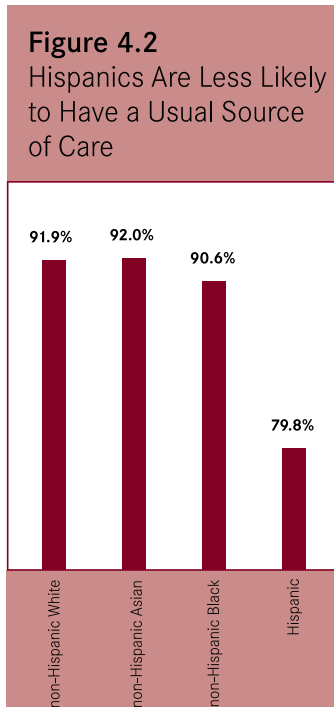


Source: AARP Public Policy Institute analysis of 2008 Current Population Survey.

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.

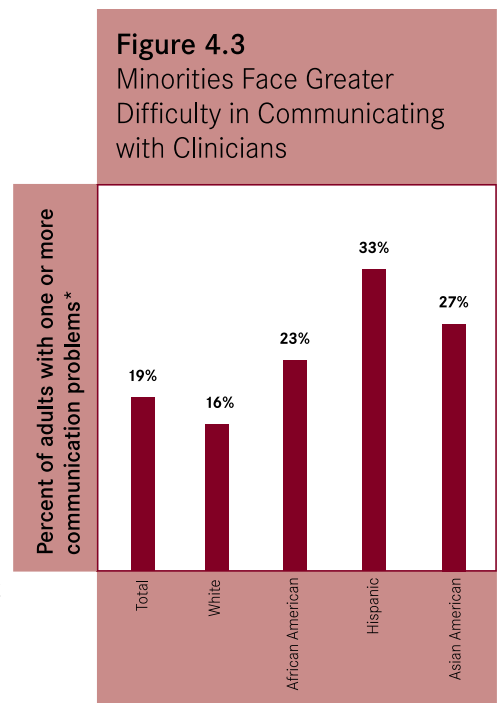
Note: Data reflect adults ages 50 to 64 in 2006.

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

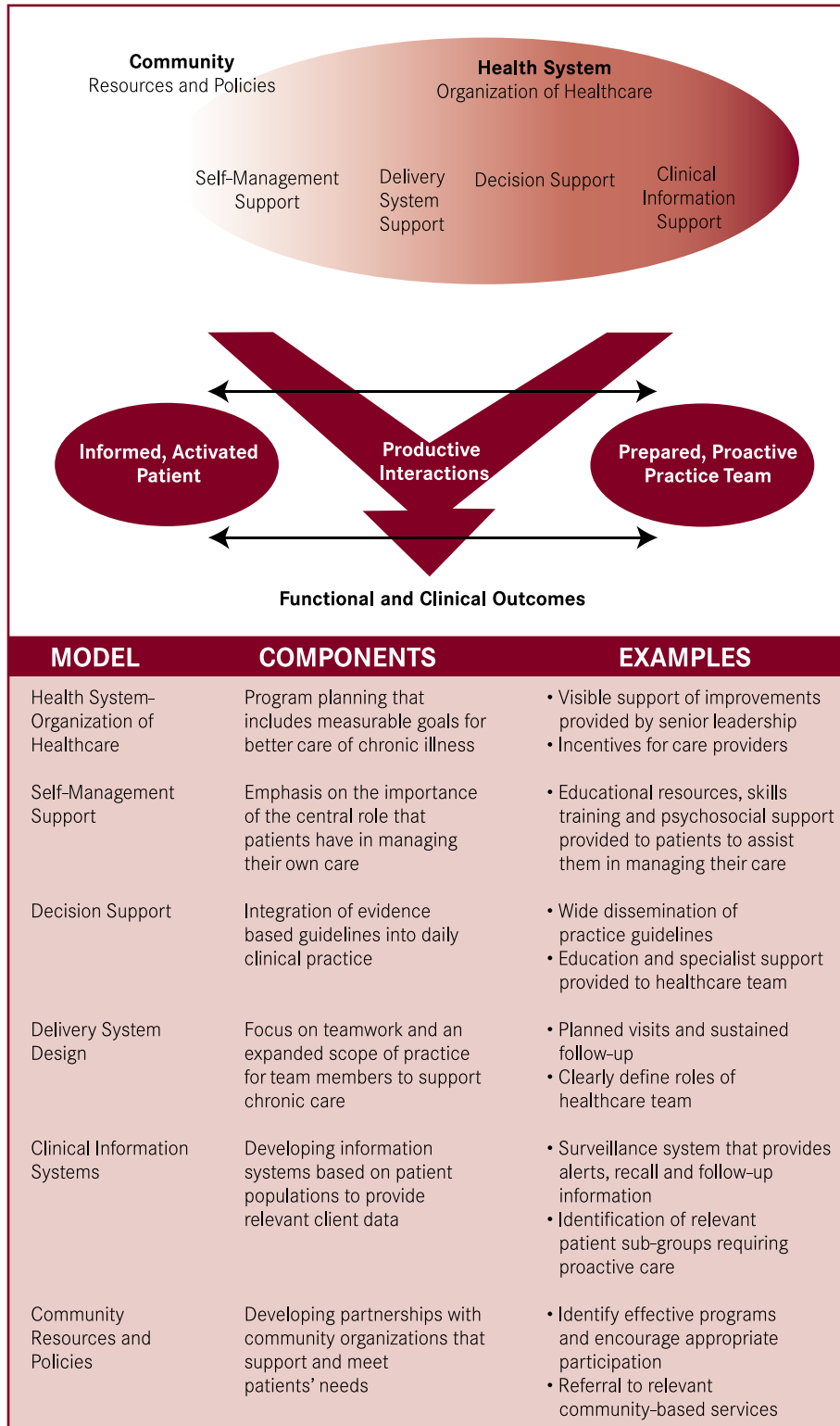
Puget Sound. The model contains six components: self-management support, community resources, organization of health care, interdisciplinary teams, decision support, and clinical information systems. Together, these elements go beyond today's often-restrictive acute care paradigm to improve patient care.

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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