

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.

