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The Many Faces of Chronic Disease

Trajectories

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Experiences

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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, Boulton, 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, Boulton, 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).

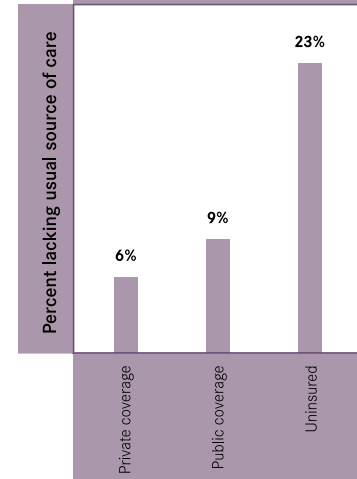
The burden of chronic disease is higher among the uninsured.

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

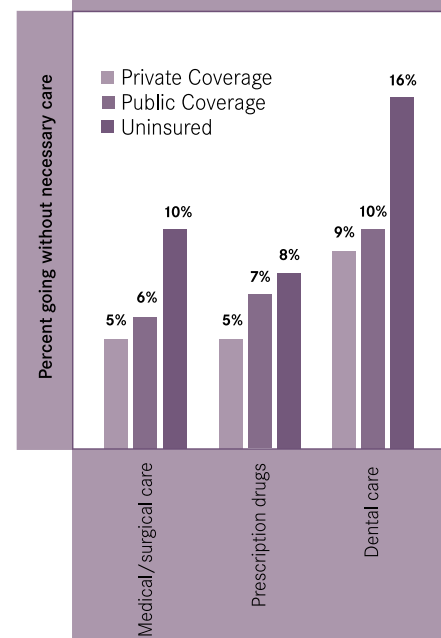
Figure 2.1:
Uninsured Adults More Likely to Lack a Usual Source of Care



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**

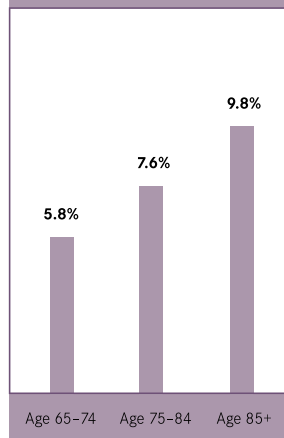
In 2005, the proportion of non-institutionalized middle old and oldest old who reported having multiple chronic illnesses was significantly greater than the proportion of their younger

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

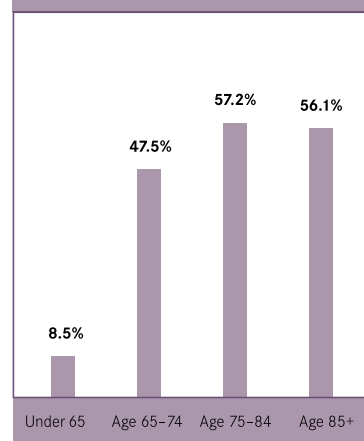
Figure 2.3:
Poor Health Status
Rises with Age



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).

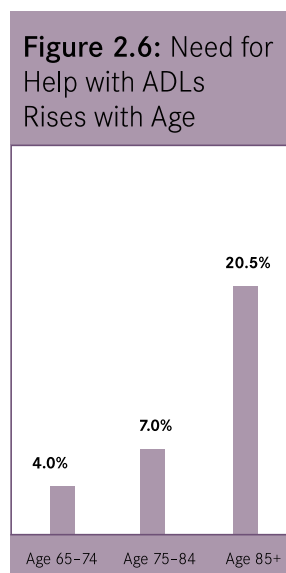
- **The oldest old have significantly more cognitive impairments than their younger counterparts**

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



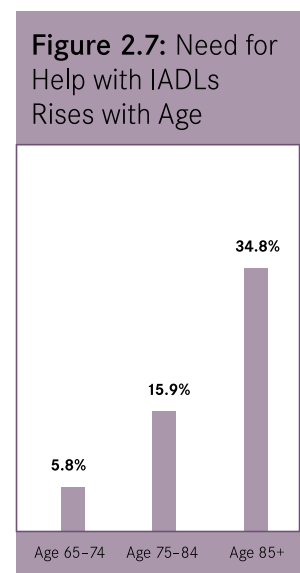
Source: AARP PPI analysis of Medical Expenditure Panel Survey, Household File, 2005.

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



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

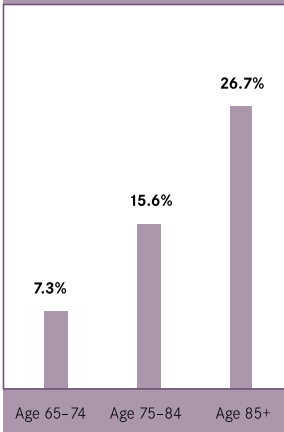
Note: Data reflect adults reporting needing help with ADLs for three or more months. Data do not include people who live in institutions.



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**

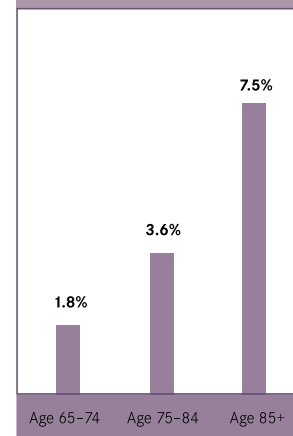
Alterations in mental health status, like depression and anxiety, can affect a person's motivation to actively participate in his or her health care and can be a significant barrier to effective self-management of chronic illness. For purposes of this report, mental health status was derived from subjective 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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