

# 3

## Patients and Caregivers Report Problems with Care

A Significant Number of Patients Had Problems

Quality Problems More Likely among Certain Types of People

Caregivers Support People with Greater Use of Health Services

Quality Problems More Likely among Caregivers Who Feel Less Capable



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

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

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

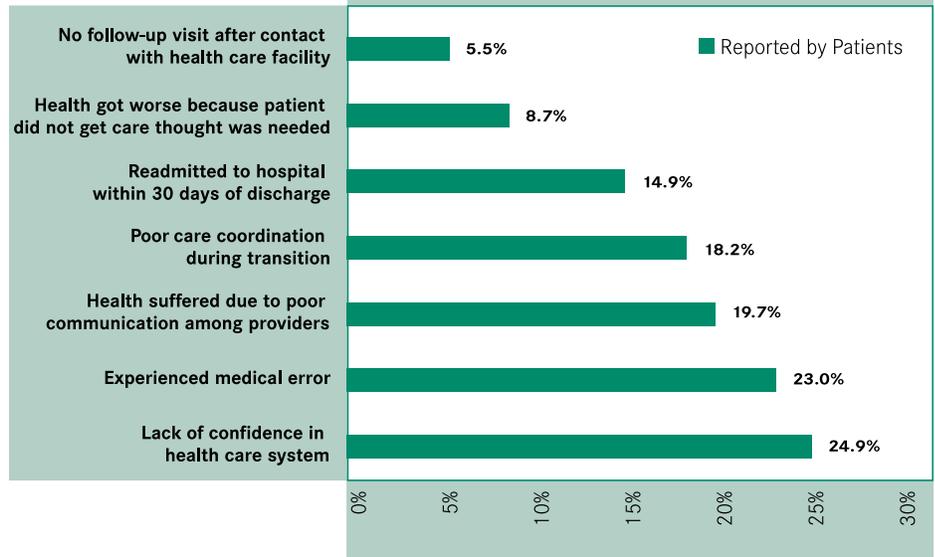
also focused on the use and need for services and support during transitions.

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

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

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

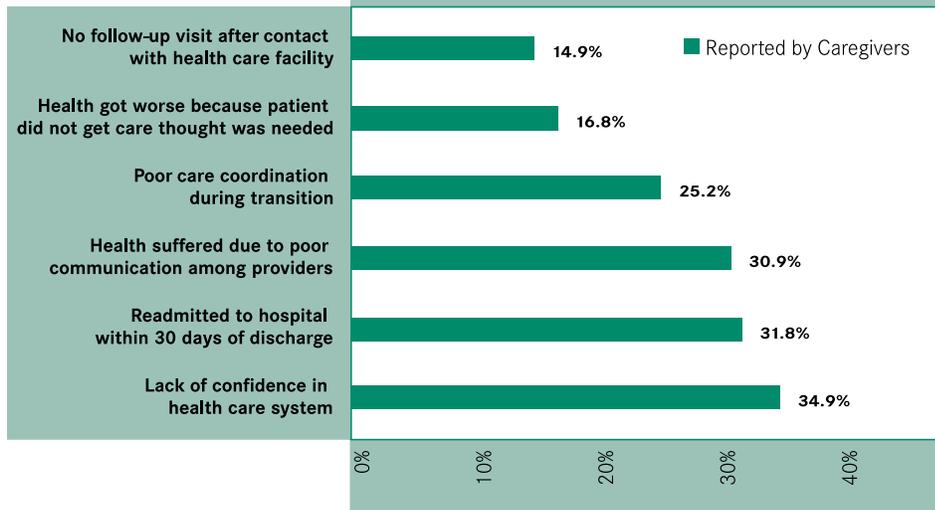
**Figure 3.1**  
Poor Outcomes Reported for People with Chronic Conditions



Source: *Beyond 50.09 Survey Report*, AARP.

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

**Figure 3.2**  
Poor Outcomes Reported for People with Chronic Conditions



Source: *Beyond 50.09 Survey Report*, AARP.

Note: Data include caregiver respondents. Sample size = 978

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

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

These findings suggest the following:

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

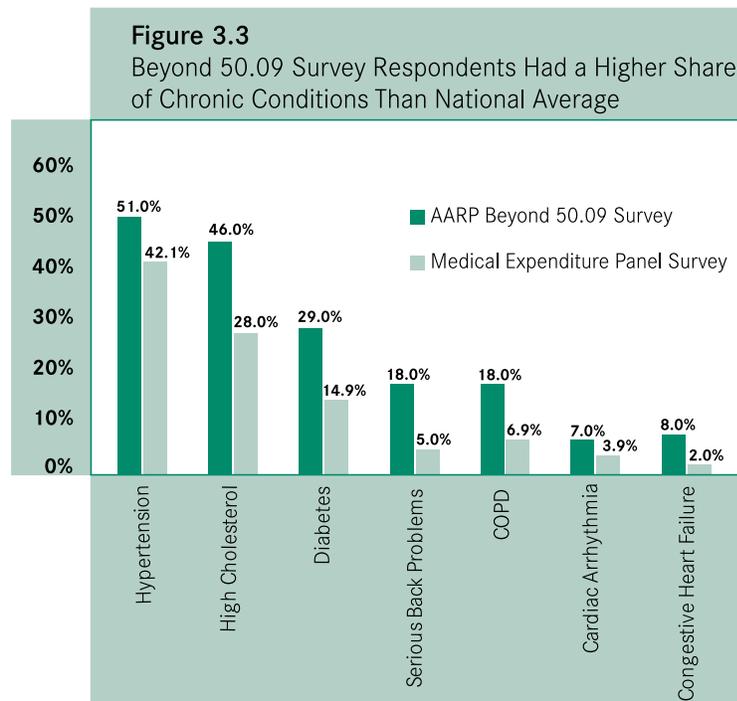
manage and monitor their chronic conditions.

### SURVEY RESPONDENTS HAD MORE CHRONIC CONDITIONS THAN AVERAGE

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

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

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



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

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

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

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

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

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

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

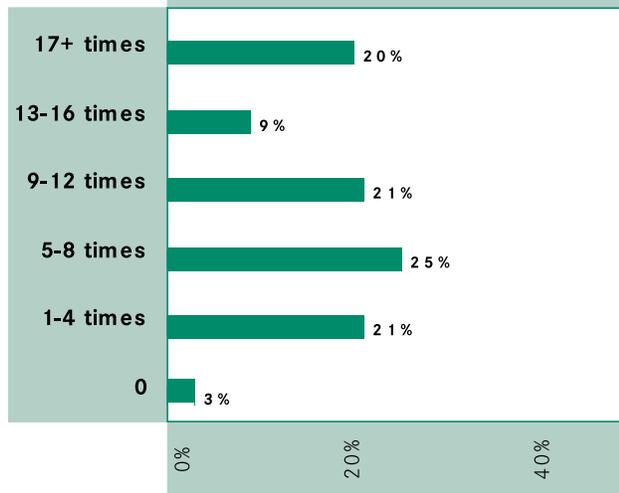
Among respondents ages 50+ with chronic conditions and a serious health episode, two in five (43 percent) said that their health was *fair* or *poor* (Figure 3.5).

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

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

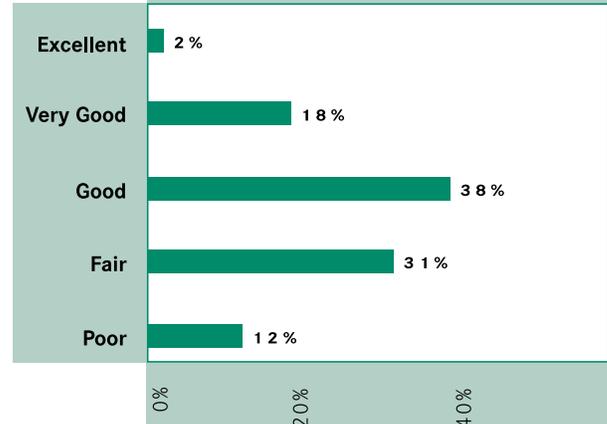
More than half (57 percent) of respondents with chronic conditions said that their chronic

**Figure 3.4**  
Most People with Chronic Illness Have Many Specialist Visits



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

**Figure 3.5**  
People with Chronic Illness Report Differing Health Status



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

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

### A SIGNIFICANT NUMBER OF PATIENTS HAD PROBLEMS

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

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

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

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

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

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

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

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

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

### **REPORTS ABOUT COMMUNICATION AMONG PROVIDERS**

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

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

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

Other issues reported by respondents included the following:

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

The pattern of responses among caregivers was similar.

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

### **QUALITY PROBLEMS MORE LIKELY AMONG CERTAIN TYPES OF PEOPLE**

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

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

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

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

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

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

### TRANSITIONAL CARE

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

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

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

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

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

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

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

### PATIENT ENGAGEMENT

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

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

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

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

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

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

### LOW ENGAGEMENT SIGNALS PROBLEMS

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

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

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

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

### ENGAGEMENT IS RELATED TO NOT GETTING CARE

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

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

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

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

### ENGAGEMENT IS RELATED TO HEALTH AND MEDICAL ERRORS

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

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

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

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

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

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

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

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

### ENGAGEMENT AND PROVIDERS

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

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

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

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

### RELATIONSHIP BETWEEN TRANSITIONS AND ENGAGEMENT

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

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

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

### CAREGIVERS SUPPORT PEOPLE WITH GREATER USE OF HEALTH SERVICES

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

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

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

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

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

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

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

### QUALITY PROBLEMS MORE LIKELY AMONG CAREGIVERS WHO FEEL LESS CAPABLE

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

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

Source: *Beyond 50.09 Survey Report*, AARP.

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

strategies might focus on helping to support caregivers.

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

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

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

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

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

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

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

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

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

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

## DETAILED METHODOLOGY

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

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

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

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

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

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

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

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

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

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

## **STUDY STRENGTHS AND LIMITATIONS**

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

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

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

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

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

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

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

## CONCLUSION

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

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

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

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

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

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

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

## ENDNOTES

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

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