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Coordinating Care for Medicare Beneficiaries: Early Experiences of 15 Demonstration Programs, Their Patients, and Providers

Report to Congress

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EXECUTIVE SUMMARY

Chronic illnesses, such as heart disease and diabetes, are the major source of costs to the Medicare program, and a major detriment to beneficiaries' quality of life. Even so, many of the acute health problems caused by chronic illnesses can be prevented if (1) patients are provided with medical care that is consistent with recommended standards; (2) patients adhere to recommended diet, medication, exercise, and self-care regimens; and (3) providers communicate better with each other and with patients. Many health maintenance organizations and indemnity insurers have developed programs or have contracted with disease management or case management providers for programs that are designed to improve patients' adherence to treatment regimens and physicians adherence to professional guidelines. However, the Medicare fee-for-service program does not provide such services.

The Medicare Coordinated Care Demonstration (MCCD), mandated by Congress, was developed to test whether these programs can achieve similar results in the Medicare fee-for-service population. In January 2002, the Centers for Medicare & Medicaid Services (CMS) selected 15 demonstration programs in a competitive awards process. Each program began enrolling patients between April and September of that year and was authorized to operate for four years.

This report provides a preliminary synthesis of findings from the first year of the demonstration programs' operations. It is too soon to produce estimates of program effects on enrolled patients' service use or costs, as an insufficient number of observations were available at the time this analysis was begun, and because it would be misleading to report on only the few months of operations for which data would be available. Thus, this report addresses the following questions:

- What types of programs and beneficiaries are participating in the demonstrations?
- What interventions are the programs implementing, and how are they doing it?
- How do patients and physicians like the programs, and how are they responding to them?

A. WHAT TYPES OF PROGRAMS AND BENEFICIARIES ARE PARTICIPATING?

The MCCD programs were selected from 58 proposals responding to CMS's solicitation. Programs were expected to have had experience operating a disease management or case management program, and to show some evidence that they had been able to reduce hospitalizations or costs. CMS took this approach to maximize the potential for showing, in a time-limited demonstration, that a successful care coordination program could be implemented in a Medicare fee-for-service environment.

Each of the programs developed its own intervention. The demonstrations are not a test of a single intervention in 15 sites, but rather, a test of 15 different interventions. This approach was taken because a previous study for CMS found that successful programs shared some common features, but did not follow a common approach (Chen et al. 2001). In return for providing the care-coordination intervention described in its CMS-approved operational protocol, each program receives a negotiated monthly payment for each beneficiary who chooses to enroll. Each program is offered only to patients living in its catchment area and meeting its approved eligibility criteria—typically, having a particular chronic illness. (Some programs restrict enrollment to patients who have had a hospitalization for the condition during the year preceding enrollment.) Enrolled patients are randomly assigned to either the treatment group, which receives the care coordination services, or to the control group, which does not. Both groups retain their normal fee-for-service Medicare coverage.

Monthly rates paid to the programs range from $50 per month for low-risk patients with one or more of several chronic illnesses in one program to $437 per month for the first nine months for all patients with congestive heart failure (CHF) enrolled in another program. The negotiated rates were based on the programs' estimates of the cost of their interventions; however, to increase the likelihood that each program would generate net savings to CMS, the rates also were tied to the programs' proposed target populations. Medicare claims data were used to estimate the expected Medicare costs of beneficiaries who met each program's eligibility requirements. If a 20 percent savings in these estimated Medicare costs for a program's proposed target population would not be enough to offset the cost of the intervention, either the proposed target population was restricted to higher-risk cases (such as beneficiaries with a recent hospitalization) or the proposed program payment was reduced to meet this constraint.

The 15 participating organizations are diverse and include 5 commercial disease management vendors, 3 hospitals, 3 academic medical centers, an integrated delivery system, a hospice, a long-term care facility, and a retirement community (see the table). The programs operate in 16 states and the District of Columbia (mostly in the northeast or Midwest); four served beneficiaries living in sparsely populated rural areas.

The programs also vary widely in the number and types of chronic conditions they target, with six programs targeting only a single condition, three taking patients with less-specific problems (for example, high-risk patients identified from administrative data by an algorithm), and the six other programs falling between these two extremes. The most common primary conditions of program patients are CHF (29 percent of patients), coronary artery disease (24 percent), and diabetes (13 percent).

Four programs drew a high proportion of beneficiaries who were older than age 85, and one program targeted and enrolled a high proportion of younger patients with disabilities. Survey data on program patients in the first six programs to begin enrolling show that, compared with all Medicare beneficiaries, the programs' patients generally were substantially more highly educated and had higher incomes. Most programs enrolled relatively few black or Hispanic patients, few patients younger than age 65, and few patients who also were enrolled in Medicaid.

CARE COORDINATION PROGRAMS PARTICIPATING IN THE EVALUATION

Host Organization	Organization Type	Service Area	Targeted Diagnoses	Study Enrollment After One Year[b]
Programs Starting in April 2002				
Carle Foundation	IDS	Rural counties in east central Illinois and west central Indiana	Heart conditions Diabetes Chronic lung disease	2,283
CenVaNet	Care coordination provider	Richmond, Virginia	Heart conditions Diabetes Chronic lung disease Cerebrovascular disease	1,074
Charlestown Retirement Community	Retirement community	Three retirement communities in the Baltimore area	Heart conditions Diabetes COPD	430
Health Quality Partners	Care coordination provider	Eastern Pennsylvania (rural)	Heart conditions Diabetes Asthma Moderate to severe hyperlipidemia or hypertension	498
Medical Care Development	Hospital consortium	Rural areas of Maine	Heart conditions	393
Mercy Medical Center/North Iowa	Hospital	Rural areas of Iowa	CHF Chronic lung disease Liver disease Stroke Vascular disease Renal failure	627
Programs Starting in June 2002				
Avera Research Institute/Avera McKennan Hospital and University Health Center	Hospital	Rural counties in Iowa, Minnesota, Nebraska, and South Dakota	CHF	318
CorSolutions	Care coordination provider	Harris County (Houston), Texas	CHF	671
Georgetown University Medical School	Academic institution	Washington, DC, and parts of Maryland and Virginia	CHF	108

continued

Host Organization	Organization Type	Service Area	Targeted Diagnoses	Study Enrollment After One Year[b]
Jewish Home and Hospital Lifecare System	Long-term care provider	Manhattan, New York City	Heart conditions Diabetes Chronic lung disease Cancer Liver disease Stroke or other cerebrovascular disease Psychotic disorder Major depressive or anxiety disorder Alzheimer's disease or other cognitive impairment	543
University of Maryland Medical School	Academic institution	Baltimore	CHF	58
Programs Starting in July–September 2002				
Hospice of the Valley	Hospice	Maricopa County, Arizona (greater Phoenix)	CHF COPD Cancer Neurological conditions	470
Qmed	Care coordination provider	Two counties in northern California	CAD	1,404
Washington University School of Medicine	Academic institution with care coordination provider	St. Louis	No specific diagnoses targeted[a]	1,425
Quality Oncology, Inc.	Care coordination provider	Broward County, Florida (Miami)	Cancer	63

Note: Heart conditions may include congestive heart failure (CHF); coronary artery disease (CAD); atrial fibrillation; and ischemic, hypertensive, or other heart diseases. Chronic lung disease includes asthma and chronic obstructive pulmonary disease (COPD). Neurological conditions include stroke, Alzheimer's disease, Parkinson's disease, and amyotrophic lateral sclerosis. See the program profiles in Appendix A for the specific diagnoses included by each program.

IDS = integrated delivery system.

[a]Washington University uses an algorithm developed by its demonstration partner, American Healthways, to target Medicare beneficiaries who are likely to become clinically unstable and to require hospitalization during the next 12 months.

[b]Enrollment figures for each program include treatment and control groups members, and generally are evenly split between the two groups. The figures also include beneficiaries who enrolled in the study but will not be included in the research sample because they are living in the same household as a member of the research sample. These individuals were automatically assigned to the same group (treatment or control) as the research sample member in their household.

Finding and convincing patients to enroll has been harder than expected for most of the programs. All 15 of the demonstration programs have been implementing their interventions largely as planned, but only 4 met their own enrollment targets for the first year, and only 4 exceeded the minimum first-year target of 686 patients that was set by Mathematica Policy Research, Inc. for the evaluation. Several programs enrolled less than half their targeted number of patients for the first year, citing initial overestimates of the number of eligible patients from their referral sources, physicians' failure to encourage their patients to enroll, high patient refusal rates, and care coordinators whose time was too limited to both recruit patients and serve those already enrolled. The programs that were most successful in enrolling patients were those that had a close relationship with physicians before the demonstration started and those with access to databases to identify potentially eligible patients.

Participants in most programs have higher preenrollment costs than did eligible nonparticipants, but a few programs may not generate net savings even if they reduce Medicare costs by 20 percent. Preenrollment costs among the 11 programs for which Medicare data were available for this report averaged more than $2,400 per month for participants in three programs, but less than $500 per month for two other programs. The programs with low-cost enrollees are likely to have difficulty achieving large enough savings to offset their intervention cost. In half of the 11 programs, more than two-thirds of enrolled patients had a hospitalization during the year before enrollment, and in most of the programs, the enrolled patients had higher costs than did eligible nonparticipants during that year. However, one program whose enrollees had preenrollment costs of less than $500 enrolled patients with preenrollment costs and admission rates that were markedly lower than those of eligible nonparticipants. It appears that this program enrolled sizable numbers of beneficiaries who did not meet all the program eligibility requirements, due to reliance on patients' self-reports and physician referrals.

B. WHAT INTERVENTIONS ARE THE PROGRAMS IMPLEMENTING, AND HOW ARE THEY DOING IT?

Our implementation analysis shows that the 15 programs differ widely in both how they implement their care coordination interventions and their links to providers. The analysis was based on telephone interviews with program staff in each program at three months after enrollment startup, and on in-person visits six months after the telephone interviews. The programs differed in their relative emphasis on four major vehicles for achieving better outcomes for patients: improving patient adherence to treatment and self-care regimens, improving coordination and communication among providers, improving physician practice, and increasing access to support services.

All but 1 of the 15 programs stress improving adherence and coordination as key objectives, but most devote less attention to convincing physicians to change their practices or to improving access to support services. All but two programs developed patient education interventions to improve patient adherence. Efforts to improve communications generally focused on teaching patients how to obtain information from their physicians; in two programs, however, care coordinators usually contacted the physicians themselves to obtain information for their patients. Programs felt that they had little leverage over physicians, and that the physicians affiliated with them mostly adhered to practice guidelines already; consequently, only five programs issued guidelines to providers or reports indicating deviations from guidelines. Efforts

to change physician practices focused mainly on tactfully notifying a patient's primary care physician when the medication or treatment the patient was receiving was not consistent with guidelines.

The programs have limited funds for paying for services that are not covered by Medicare. Thus, their efforts to improve access have consisted mainly of learning about and helping patients arrange for services available from other community sources. However, even these efforts are limited; fewer than 10 percent of patients received help arranging for transportation or home care services during their first six months in the programs, according to program records.

All the programs recognized the importance of integrating their efforts with those of their patients' physicians, and all but one either had preexisting links between the care coordinators and physicians or made conscious efforts to facilitate the creation of such bonds. Efforts included (1) inviting physicians to serve on program advisory boards or identifying local opinion leaders as program champions; (2) stationing the care coordinators in the same location as the physicians or pairing a specific care coordinator with each physician, so that all of that physician's program patients had the same care coordinator; and (3) holding regular meetings between care coordinators and physicians or issuing periodic reports. Three programs had preexisting links and used all three approaches to foster integration. Two programs took none of these approaches to building relationships.

Finally, programs varied in their approach to care coordination, ranging from a narrow but in-depth focus on problems associated only with the targeted conditions to a broader focus encompassing all of the patients' medical conditions, as well as psychological needs. Three programs focused their interventions on the targeted conditions, with little attention to comorbidities or social barriers to better adherence; one program took the opposite approach. The 11 other programs fall somewhere between these extremes of the continuum. Although the 11 established guidelines for the treatment of the primary targeted conditions, they also devoted substantial attention to dealing with major comorbidities, and they sought ways to address psychosocial barriers as well.

The programs assessed patients in person, but most subsequent contacts were by telephone. A more comprehensive examination of the six programs that first began enrolling patients (in April 2002) shows that these programs used a variety of assessment tools, and that they differed substantially in their caseloads. The average caseload in the sixth month of operations for the six programs was 25 patients per care coordinator, but this ratio ranged from 4 to 52. Patients typically were assessed in their homes, with 23 to 72 percent receiving their initial assessment contact within the first two weeks after enrollment. Programs cited competing demands on care coordinators' time as the primary reason for not assessing patients more quickly. The assessments culminated in care plans to fill the gaps in the patients' knowledge and treatment. These plans were developed collaboratively with patients and, when appropriate, with the patients' families. Most contacts after assessment were conducted by telephone, but one program made more than 80 percent of its patient contacts in person.

The early programs attempted to monitor patients at least monthly, but they relied little on electronic monitoring. The six early programs established guidelines specifying a minimal frequency for monitoring patients, but they relied on the discretion of their care coordinators to determine whether a given patient should be monitored more frequently. Some programs

classified patients by acuity level, with different monitoring frequencies recommended for the different levels. Only two of these six programs made any use of electronic monitoring devices, and both did so only for a fraction of their patients; however, four of the programs that started up later made extensive use of such devices. The content of the monitoring calls also varied widely, including reinforcement of the educational effort; checking on patients' progress with self-care and adherence to medication, diet, and exercise regimens; asking about symptoms and unmet needs for assistance; and asking about routine or emergency service use or changes in physicians' treatment plans.

Two of the first six programs to start up had no system for learning about adverse events that their patients experienced and had to rely on the patient for such information. The four other programs were notified in some way by their data systems.

Only one early program made substantial demands on physicians' time. Care coordinators make tactful, patient-specific suggestions about any treatments that deviated from guidelines. All of the early programs asked physicians to review potential enrollees for appropriateness for the intervention, and they all expected the physicians to respond to care coordinators' requests to discuss specific patients, but they varied in how involved they expected physicians to be in the care planning and other program activities. Two required physicians to provide input to the plans, two required physicians to sign off on plans, and two simply mailed copies of the plans to the physicians. In some programs, care coordinators had frequent, informal contacts with physicians. Care coordinators in two of the six early programs held quarterly or semiannual meetings with the physicians to discuss their patients. Three of the programs periodically provided physicians with written reports on patients.

Three early programs paid the patients' primary care physicians, either for their attendance at scheduled meetings or through a monthly capitation for each patient enrolled. The three other programs did not pay physicians.

When patients in three of the early programs were not receiving care consistent with the guidelines, the programs' care coordinators tried to work collaboratively with the patients' physicians to determine whether, and how, to rectify the situation. By contrast, as part of its approach to improving clinical practice, one program expected its care coordinators routinely to compare care with the guidelines, and to contact the physicians about any discrepancies. (Care coordinators in the other two programs were not responsible for ensuring physician adherence to guidelines.)

Nearly all the early programs devoted a high level of attention to improving patient education about adherence to treatment and self-care regimens. Program-supplied data suggest that 80 percent of patients in the six early programs had contacts with their care coordinators during which educational issues were addressed, with program-specific rates ranging from 71 to 96 percent. The proportion with contacts to explain medications (33 to 93 percent) or tests (12 to 65 percent) were somewhat lower, but still substantial in most programs. Five programs developed their own educational curricula; the other adapted previously published materials. All six programs routinely assessed how well the patients were responding to the educational interventions. Two did so by tracking clinical indicators and two did so by quizzing the patients; the other programs relied on less formal conversations during the monitoring calls. Three programs taught patients how to locate community resources.

C. HOW DO PATIENTS AND PHYSICIANS LIKE AND RESPOND TO THE PROGRAM?

Survey data on small samples of early patients and their physicians in a subset of the programs suggest that the programs are popular with both groups. The patient surveys generally were conducted 7 to 12 months after patients enrolled. Physicians were surveyed about 12 to 15 months after the program in which their patients were enrolled began operations.

The earliest-starting programs have pleased patients and appear to have increased patients' understanding of their disease and their satisfaction with care overall, but they have not increased rates of adherence to medication, diet, and exercise regimens in this initial sample. Nearly 90 percent of the first 735 program patients interviewed stated that they had received services from their programs. Among that group, 80 to 90 percent rated as very good or excellent their care coordinators' knowledge, ability to explain diet and exercise regimens, and help with self management and service arrangements. On most measures, they rated the help they received more highly on average than did the 13 percent of control group members who reported obtaining care coordination services from other sources. Patients cited a variety of factors when asked to identify the most important way in which their care coordinators helped them. However, they mentioned "staying in touch" and "having a caring attitude" most frequently, suggesting that care coordinators are generally successful in establishing the bonds with patients that are important if their advice is to be sought or taken seriously. Compared with the randomly assigned control group, the treatment group patients reported significantly better understanding of their health problems, better communication among their providers, greater improvements in their ability to obtain answers to questions about their condition, greater improvements in their ability to obtain appointments for tests and procedures, and better ratings of the overall quality of care they received. The programs have not had any apparent effect on either the ease of sorting out conflicting advice from providers or the quality of explanations about possible side effects of medications, but relatively few control group patients reported having those problems, so there was little opportunity for major improvement on these measures.

Despite these positive and sometimes large effects on consumer satisfaction, we find no significant differences between the treatment and control groups on adherence. Treatment group patients were only slightly more likely than control patients to report following a healthy diet or exercising regularly, and they were equally likely to report not missing any doses of prescribed medication during the past week.

Physicians were very satisfied with the program, thought it improved patient care, and would recommend it to patients and providers. Interviews with 112 primary care physicians of program patients revealed that these providers felt the program reduced their telephone time, had mixed opinions on whether it increased or decreased paperwork, and believed it influenced the frequency of office visits. Some physicians believed the program led to more office visits, and some thought it reduced visits, but both groups felt the induced changes were appropriate. Physicians rated the care coordinators' clinical judgment and competence highly, and 95 percent found the reports coordinators sent them to be very or somewhat useful. More than half the physicians said that the care coordinators had detected patient problems that they had not known about, and they reported high levels of satisfaction with the way that care coordinators dealt with

issues. Half the physicians stated that the care coordinator had influenced their clinical decisions in some cases, and 92 percent rarely or never disagreed with the care coordinators.

Most physicians felt that the programs did a good job of obtaining social services for patients, but they were less sanguine about whether the programs could improve patients' ability to obtain necessary medical appointments or prescription drugs. The physicians believed that the care coordinators helped by coordinating efforts with the patients' families, and by reducing the fragmentation of care. Overall, 92 percent would recommend their programs to patients and colleagues.

D. LIMITATIONS AND FUTURE ANALYSES

Given that the programs had been operating only for one year at the most when this analysis began, many of the most important research questions for the evaluation could not be addressed in this preliminary synthesis report. The report provides very limited estimates of impacts on patient satisfaction and adherence, and no estimates at all of effects on key outcomes, such as the use and cost of Medicare services. Furthermore, some of the implementation findings are based on a subset of the programs, and the patient survey results are for only the earliest enrollees in the first six programs to begin enrolling. The survey results are dominated by two of the programs, which accounted for nearly half the observations. Thus, the findings may well be quite different when the full sample becomes available.

These shortcomings will be rectified in the second synthesis report, which is due in August 2005 (40 months after the first MCCD program began enrolling patients). That analysis will present program-specific estimates of impacts on the quality of care, service use, costs, adherence behavior, patients' satisfaction, patients' disease-related limitations, and physicians' satisfaction. The report will synthesize the findings from the implementation and impact analyses across the 15 programs to identify likely reasons why some of the 15 had larger effects than did others, and it will assess how impacts vary with patient characteristics and conditions and over time.

E. THE PROGRAMS OFFER SUBSTANTIAL POTENTIAL FOR IMPROVING PATIENTS' LIVES

Although none of our impact estimates available at this time would lead us to conclude that the demonstration programs are having large effects on patients' behavior or outcomes, these preliminary findings do suggest that such effects might be observed when the full set of data become available for all of the programs. Physicians have been responding favorably to the programs—an important factor, given the widespread recognition that few care coordination programs are likely to succeed without significant cooperation and reinforcement from patients' physicians.

The absence of large effects on the patient adherence measures may be somewhat discouraging, but it does not necessarily imply that the programs are not having any effect on patient behavior. Relative to the control group, program patients reported better access to information and appointments, better communication among their providers, and greater

understanding of their health condition. Furthermore, the finding that program patients were not significantly more likely to report eating a healthy diet or exercising regularly may have a positive explanation—it is possible that, as a result of program education, the treatment group had higher standards as to what constitutes "healthy" or "regular." If that is true, their actual adherence may be better than the control group's, but the survey measures reported here may not reflect it. More-detailed measures on disease-specific adherence behavior and self-care will be examined when the full survey sample becomes available. In addition, in many cases, behavioral change takes time; some changes do not occur until patients have experienced an adverse event that makes them recognize the value of adhering to advice from their physicians or care coordinators.

Finally, we know from conversations with care coordinators that their interventions are making important improvements in the lives of some of their patients. Although the following actual case does not imply that the programs will reduce Medicare costs in the aggregate, or that they will lead to statistically significant improvements in patients' adherence to treatment regimens, it does provide evidence of the programs' *potential* to do so, and of the real impact that the programs are having for some patients.

> Mr. Jones is a 77-year-old retiree and widower. He has diabetes, coronary artery disease, hypertension, and several other chronic conditions and has been treated for prostate cancer. His leg was amputated above the knee. He suffers from depression as a result of the recent deaths of his wife and brother. He takes 14 medications. Serious exacerbations of his conditions have brought him to the hospital many times in recent years.
>
> Following assessment, his care coordinator developed a plan to address his most pressing needs: severe abdominal pain from chronic enteritis resulting from radiation therapy; incapacitating pain at the site of his amputation; and depression. Program interventions included support and education in several areas. The care coordinator provided education on dietary changes to control the enteritis and taught Mr. Jones to recognize symptoms signaling the need to contact his physician before an obstruction developed that would require hospital care. He also was taught how to take pain medication correctly, and he learned that appropriate use would not lead to addiction, as he had feared. Mr. Jones was provided with education about diabetes care that covered the importance of testing his blood glucose twice a day, modifying his diet, and performing regular self-monitoring, such as foot examinations.
>
> The program also referred him to a bereavement group at a local hospital. Despite his initial resistance, Mr. Jones found the group so useful that he joined a second one, at his church. In addition, the care coordinator helped him to develop a system to ensure that he took all his medications each day, helped him have his prosthesis adjusted for greater comfort, and encouraged him to join a fitness center (after having a cardiac stress test). After a year in the program, Mr. Jones has had only had one 1-day hospital admission.

If enough program patients have experiences like those of Mr. Jones, the demonstration programs may significantly reduce patients' need for expensive hospital stays, reduce their total Medicare costs, and improve their well-being.

I. OVERVIEW OF THE DEMONSTRATION AND EVALUATION

Chronic illness, which affects millions of Medicare beneficiaries, is a major source of misery for beneficiaries and the primary driver of costs to Medicare. However, many of the acute problems that people with chronic illnesses experience, and the resultant psychic and monetary costs, can be prevented if (1) patients are given the proper explanations about and care for their condition and treatment; (2) patients take good care of themselves by adhering to medication, diet, and exercise regimens; and (3) physicians know about the treatments and recommendations that other physicians are providing to their patients. Although health maintenance organizations (HMOs) and commercial insurers have developed or contracted with disease management and care management programs to help to make these changes in patient and provider behavior, no such programs exist in Medicare fee-for-service.

The purpose of the Medicare Coordinated Care Demonstration (MCCD) is to determine whether disease management and care management programs can improve health outcomes for and reduce the Medicare costs of chronically ill beneficiaries. The evaluation will test whether the demonstration programs accomplish these goals, estimate the size of the effects, and assess what program features are associated with the largest effects. This report describes the interventions and discusses some early findings on enrollment and on patient and physician satisfaction.

A. INCIDENCE AND TREATMENT OF CHRONIC ILLNESS

1. What Is "Chronic Illness"?

Improving care for a relatively small proportion of Medicare beneficiaries—those with serious chronic illness—has tremendous potential for reducing total costs to Medicare, as well as for improving the lives of these beneficiaries. In 1998, the most expensive 6 percent of all

Medicare enrollees accounted for half of all Medicare program payments, and the top 14 percent accounted for 76 percent of all Medicare payments (Gluck and Hanson 2001). The great majority of these most expensive beneficiaries had multiple chronic illnesses.

Defining a chronic illness is the subject of considerable debate. Although many researchers, advocates, and organizations have developed their own definitions, a group of patients, physicians, and policymakers that set out to develop a consensus definition was unable to do so (Carter et al. 2002). Furthermore, some of the definitions proposed by others are so broad as to include the great majority of Medicare beneficiaries, thereby rendering the definition relatively useless for this population. Other definitions focus on functional impairments and long-term care needs, ignoring the many beneficiaries who do not need such services, but who nevertheless have ongoing health problems that adversely affect their lives and create a need for acute care.

For this study, we define chronic illness as a medical condition that (1) is persistent and incurable but controllable with treatment; (2) if uncontrolled, leads to repeated acute health crises and hospitalizations within a few weeks, and to steady deterioration during the next few years that is accompanied by increasing disability, increasing complications, worsening quality of life, and increased risk of death; and (3) requires substantial, sustained efforts by both patients and providers to maintain control of the condition through self-care, adherence to medication regimens, high-quality medical treatment, and constant monitoring and timely intervention for early signs of exacerbation. Our definition includes some people with few impairments, and many with extensive impairments. The key feature of our definition is that the course of rapid deterioration interspersed with acute exacerbations often is preventable through proper medical treatment and self-care.

Although no estimate of the number of Medicare beneficiaries who meet our definition is available, nearly half (48.4 percent) of Medicare beneficiaries were treated for one or more of the

following eight chronic illnesses in 1997: non-arterial heart disease, cancer, diabetes, coronary artery disease, stroke, pulmonary/respiratory problems, anemias, or liver/kidney problems. The average annual cost to Medicare for this group in 1998 was more than three times the average for Medicare beneficiaries without any of these conditions, accounting for three-fourths of total Medicare costs (Table I.1). Many beneficiaries with any of the eight conditions suffer from a poor quality of life, and many are hospitalized frequently. (According to Merrill [2003], for example, nearly three-fourths of all Medicare patients discharged from a hospital after receiving treatment for congestive heart failure are readmitted within one year.) Problems of high costs and poor quality of life are exacerbated for individuals with multiple chronic conditions. Our estimates show that, in 1998, the 11 percent of beneficiaries with three or more of the eight conditions had costs 6.1 times larger than the cost of beneficiaries with none of the conditions, and they accounted for one-third of all Medicare costs.[1] Beneficiaries with five or more of the conditions had costs that were more than 10 times that of beneficiaries who were free of these chronic illnesses.

2. What Can Be Done About Chronic Illness?

Perhaps most frustrating for beneficiaries, providers, and policymakers alike is that many hospitalizations related to chronic illness are preventable. Medicine and Health 2003 has estimated that one-fourth of people with eight or more chronic conditions have an unnecessary hospitalization during a given year. The responsibility is shared by patients and providers. Providers often fail to teach their patients how to follow medication, diet, exercise, and self-care regimens, and many patients have difficulty adhering to these regimens even if they do understand them. Many patients also need help curbing unhealthy behaviors, such as

[1]We obtain this estimate by calculating a weighted average of the ratios in Table I.1 for Medicare beneficiaries with three, four, and five or more conditions.

TABLE I.1

PERCENTAGE OF BENEFICIARIES WITH CHRONIC DISEASES AND MEDICARE COST PER MONTH, 1998

Conditions	Percentage with Treatment for Condition in 1997	Average Cost per Month in 1998 (Dollars)	Ratio of Cost with Condition to Costs with No Conditions	Group's Percentage Share of Total Medicare Cost[a]
Heart Disease (Non-arterial)[b]	21.1	918	4.1	41.6
Diabetes	14.8	814	3.6	25.9
Pulmonary/Respiratory	13.6	955	4.2	27.9
Arterial	12.7	953	4.2	26.0
Anemias	11.6	1,059	4.7	26.4
Stroke	9.6	911	4.0	18.8
Cancer	3.8	1,050	4.7	8.6
Liver/Kidney	3.2	1,818	8.1	12.5
Any of the Eight Conditions	**48.4**	**708**	**3.1**	**75.1**
Number of Different Conditions				
0	51.6	225	1.0	24.9
1	24.6	435	1.9	23.0
2	12.6	701	3.1	19.0
3	6.4	1,037	4.6	14.2
4	3.0	1,493	6.6	9.6
5+	1.8	2,409	10.7	9.3

Source: Calculations performed by Mathematica Policy Research, Inc. on the Medicare five percent sample.

[a]The share of total Medicare costs for individuals with specific diagnoses sums to more than 100 percent because many beneficiaries have multiple conditions and therefore are included in multiple rows.

[b]Heart disease includes heart failure, cardiomyopathy, valve disease, hypertensive heart disease, myocardial infarctions (heart attacks), angina, other ischemic heart disease, pulmonary heart disease, diseases of the pericardium or endocardium, and cardiac dysrhythmia. These conditions include all ICD9 codes from 391-429, except for 392, 399-401, 405-409, and 418-419.

smoking and overuse of alcohol, but do not receive it. They also do not receive proper preventive care tests; for example, 45 percent of people with diabetes do not have their blood glucose levels tested regularly, and a similar percentage fail to receive annual retinal examinations (Bodenheimer 1999). Again, this failure sometimes is due to physicians neglecting to perform or recommend these tests, and sometimes to patients refusing or forgetting to make or keep the necessary medical appointments. In either case, the patient's risk of experiencing acute exacerbation increases. These problems are compounded by poor communication among a given patient's multiple providers, who may sometimes give the patient conflicting advice.

The shortcomings of standard American medical care for chronic illness have been well-documented (Jencks et al. 2003; McGlynn et al. 2003; Institute of Medicine 2001; Schuster et al. 1998; and Steinburg 2003). A number of reasons for these shortcomings have been suggested, including inadequate preparation in medical school, insurers not covering providers' care coordination activities, inadequate data systems, and problems with the basic structure of the U.S. health care system (Berwick 2002). Other reasons given for failure to provide appropriate care may seem shocking to patients and policymakers. For example, physicians sometimes do not prescribe potentially beneficial medications (or do not prescribe the optimal dosage) because it takes substantial amounts of their time to titrate the proper dosage—time for which they are not fully reimbursed by Medicare.[2] Because of these shortcomings, patients do not receive the

[2]This somewhat surprising comment was made by a cardiologist at a heart failure conference, in response to a question about why angiotensin-converting enzyme (ACE) inhibitors are not prescribed for *all* patients with congestive heart failure (CHF), given the widespread promulgation of this recommendation. Other physicians have agreed with this assessment. The problem lies with the reimbursement system. Repeated blood pressure readings must be taken in order to titrate the optimal ACE inhibitor dosage. Although patients can take the readings themselves and call them in to their physician's office, none of the nurse's or physician's time to collect, assess, and respond to this information is reimbursed. Requiring patients to come to the office every other day is burdensome and impractical as well. Numerous

care they need, do not understand what symptoms are signals that they should contact their physicians, or do not adhere to recommended regimens for diet, medication, and exercise. As a result, their health declines, symptoms increase in severity, and acute episodes occur, which in turn, often lead to admission to a hospital or emergency room.

A wide variety of "disease management" or "case management" programs have been developed to reduce the likelihood and frequency of these avoidable adverse events and their concomitant personal and financial costs. Although the programs have used a highly diverse array of methods, most have relied on two methods to generate large reported reductions in the need for hospitalizations: (1) patient education about treatment regimens and the importance of adhering to them, and (2) telephone or in-person monitoring of patients' symptoms, adherence, and self-care between office visits (see, for example, Wasson et al. 1992; Rich et al. 1995; and Riegel et al. 2002). Some programs have shown that encouraging physicians to use evidence-based practices and feeding back to them information on their patients, gathered from monitoring calls or in-home visits, has moderated medical costs while improving the standard of care (see, for example, West et al. 1997; and Sidorov et al. 2002). Many of the most successful programs also develop mechanisms to improve communication across providers—such as team meetings, telephone updates by case managers, and sharing of medical records—thereby reducing care fragmentation and the amount of conflicting advice given to patients. Finally, these programs sometimes help patients to follow treatment regimens by guiding them to beneficial, non-

(continued)
medications for chronic illness require this type of uncompensated interaction (for example, insulin for diabetes). Furthermore, before adjusting a medication dosage, a physician must gather additional information about his or her patient to ensure that the patient's adverse symptoms (such as elevated blood pressure) are not due to stress, a change in diet, or some factor other than the dosage of the medication.

Medicare-covered services that the patients may not have realized are available locally, such as pharmacy assistance, subsidized transportation or meals, and medication scheduling aids.

HMOs and commercial insurers use disease management or case management programs extensively to control costs, typically purchasing these services from commercial vendors. Although the vendors claim to produce large savings in the private sector, the efficacy of disease management has received mixed reviews in the literature. The premise behind care coordination and disease management is undisputed, and a number of well-designed randomized trials have shown some programs to be quite effective (see, for example, Rich et al 1995; Naylor et al. 1999; Leveille et al. 1998; and Riegel et al. 2002). However, other studies have found that case management programs have no effect (Fitzgerald et al. 1994) or can *increase* overall spending (Weinberger et al. 1996).

In response to the growing number of Medicare beneficiaries and the rapidly increasing costs associated with their care, proponents of care coordination have urged the adoption of these programs by Medicare fee-for-service (FFS), the dominant form of Medicare coverage for beneficiaries. In turn, the U.S. Congress has mandated a series of demonstration projects, as required by the Balanced Budget Act of 1997, to identify an appropriate combination of disease management features that simultaneously improve health outcomes for chronically ill Medicare FFS beneficiaries and reduce the cost associated with the care of these individuals.

3. What Exactly Is "Care Coordination"/"Case Management"/"Disease Management?"

The terms "disease management," "case management," and "care coordination" are related, but they mean different things to some researchers, practitioners, and policymakers, while are used interchangeably by others. The Disease Management Association of America defines "disease management" as "a system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant" (Disease

Management Association of America 2003). According to the association, the goals of disease management include improving the provider–patient relationship, using evidence-based practice guidelines and patient empowerment strategies to prevent exacerbations and complications of disease, and regularly measuring outcomes. The National Committee for Quality Assurance and URAC both offer accreditation and certification of disease management programs based on the programs' use of evidence-based clinical guidelines, patient education to improve self-management, and provider education to provide clinically appropriate care (National Committee for Quality Assurance 2003 and URAC 2003).[3]

"Case management" has very different interpretations in different circles. For example, the long-term care community uses case management to refer to the arrangement of home- and community-based long-term care services for frail, elderly individuals. The Case Management Society of America defines case management in a manner that encompasses needs for both acute care and long-term care. According to this definition, case management shares disease management's focus on improving communication, but it includes a more global emphasis on assessment and planning. The society's charter defines case management as "a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes" (Case Management Society of America 2003).

Finally, the term "care coordination" has no well-established definition. Rather, it is generally understood to mean a process of improving communication among the various medical

[3]URAC's original name was the Utilization Review Accreditation Commission. The organization changed its name in 1996 to URAC.

professionals with whom patients come in contact and between these professionals and the patients themselves (and their families).

For the purposes of this report, we use "care coordination" to encompass the entire set of programs in the MCCD, and we classify each program on a continuum defined by the extent of the program's focus on care related specifically to a small number of targeted chronic conditions. Programs at one end of the spectrum target a few (one to four) chronic conditions and devote little attention to caring for a patient's comorbidities. Programs at that end of the spectrum tend to have very structured interventions to educate patients and promote the use of evidence-based guidelines by physicians. They generally rely heavily on sophisticated data systems, and they devote little or no attention to either arranging non-medical services for the patients or dealing with environmental factors that may affect patients.

Programs at the opposite end of the spectrum target patients with a range of diseases or problems, and rather than focus on the specifics of caring for a particular disease, focus on identifying and overcoming the barriers that prevent patients from stabilizing their health status. Patients may or may not have a single condition that is primarily responsible for most of their health problems, and comorbidities are the rule, not the exception. The interventions tend to be less structured, with the care coordinators using their judgment to determine the best approach to helping each patient. Programs at this end of the spectrum place strong emphasis on arranging for non-medical services, and on identifying and overcoming a patient's psychological or social barriers to improved health and well-being.

Although we eventually will look for associations between program effectiveness and where the programs fall on this continuum, in this report we focus our attention on describing how the programs accomplish the three basic functions of care coordination described by Chen et al. (2000):

1. ***Thorough Assessment and Planning.*** Includes recognizing and addressing all of a patient's significant problems (medical and non-medical), identifying the patient's goals, and developing a practical plan of care
2. ***Implementation and Delivery.*** May include building relationships with the patient, the patient's family, and his or her primary care physicians; providing support; arranging services; delivering evidence-based clinical interventions; and educating the patient about his or her health problems and self-care techniques
3. ***Reassessment and Adjustment.*** Includes performing periodic reassessments, ensuring accessibility, and promptly making the necessary adjustments to the plan of care

Figure I.1 elaborates on the various components of care coordination programs. Few programs perform all of these activities, and how they do them—and how *well* they do them—varies greatly.

B. CMS'S EFFORTS TO INTRODUCE CARE COORDINATION TO MEDICARE

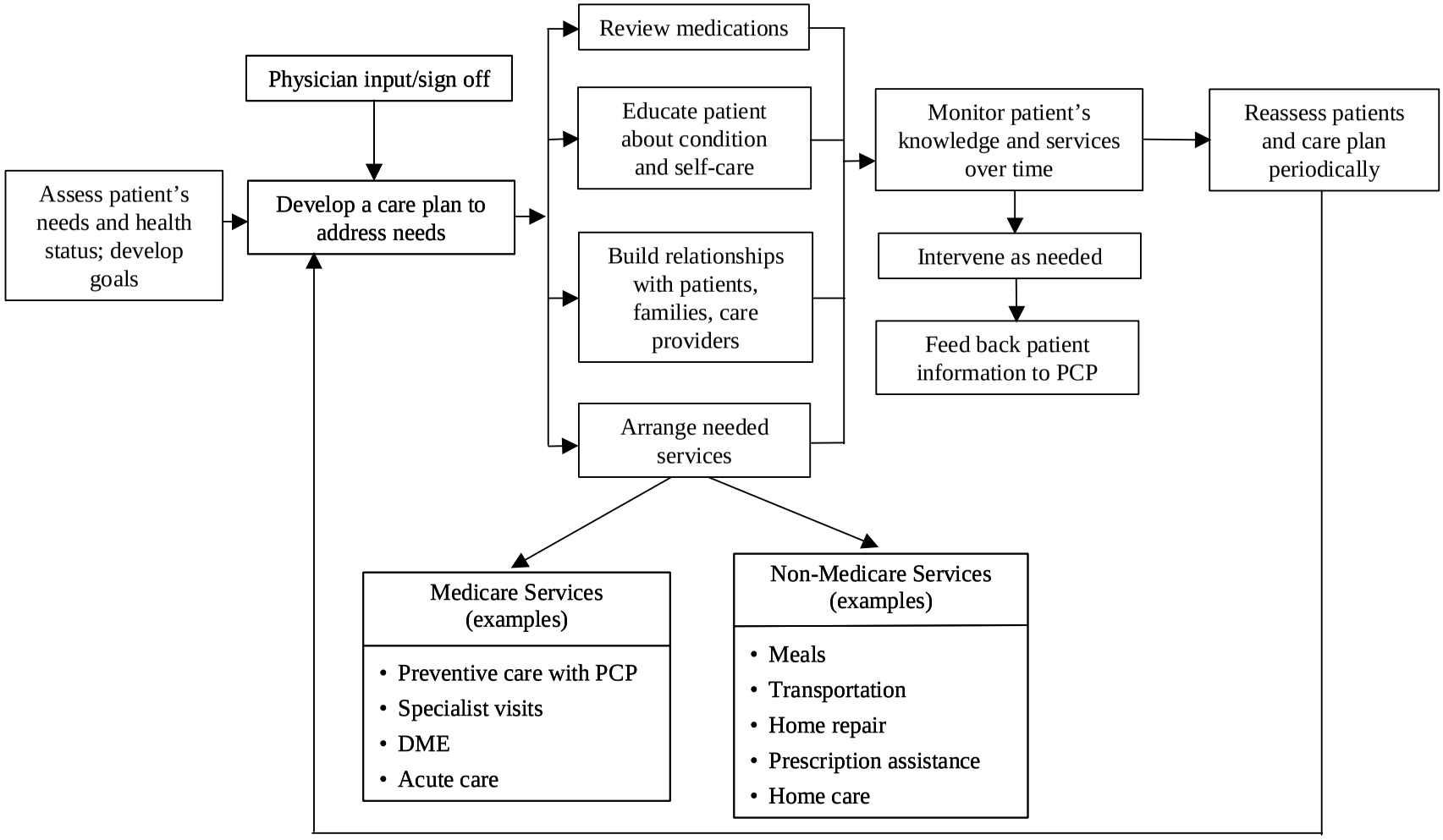
The Centers for Medicare & Medicaid Services (CMS) sponsored two previous projects to assess the potential benefits of bringing care coordination programs to the traditional Medicare FFS program. These efforts have led to the MCCD programs, which we assess in this report, and to new demonstrations in various stages of planning.

1. Previous CMS Demonstrations and Design Projects

The Omnibus Budget Reconciliation Act of 1990 mandated case management demonstrations aimed at improving health outcomes and reducing costs for Medicare beneficiaries with certain catastrophic illnesses. From October 1993 through November 1995, CMS sponsored Medicare case management demonstrations operated by three, quite different entities: (1) a tertiary-care teaching hospital, (2) a peer review organization, and (3) a holding company of a large insurer. (Peer review organizations are now known as quality improvement organizations.) All three demonstrations targeted beneficiaries with CHF; the peer review organization also targeted chronic obstructive pulmonary disease, and the teaching hospital

FIGURE I.1

CARE COORDINATOR ACTIVITIES



Note: Not all programs perform all of these tasks. Programs also differ widely in the amount of staff time and program resources devoted to the various activities, and in how they accomplish a given task (for example, telephone versus in-person contacts, frequency of contacts, shared data systems, and computerized telemonitoring of patients).

DME = durable medical equipment; PCP = primary care physician.

targeted eight diagnostic groups**.** Random assignment placed consenting eligible beneficiaries either in a control group that received regular Medicare benefits or in a treatment group that received case management in addition to regular Medicare benefits. The three demonstrations varied in their structuring of case management activities, use of nurses and social workers, amount of in-person client contact, and emphasis on patient education versus service coordination.

An evaluation of the three demonstrations found that all of the projects succeeded in developing targeting criteria to identify beneficiaries at high risk of hospitalization and costs, but that all of them failed to either reduce health care costs or improve patient self-care or symptom control during the demonstration period (Schore et al. 1997 and 1999). (One program significantly *increased* hospitalizations.) Four factors contributed to program failure: (1) physicians were not integrated into the interventions and therefore neither actively cooperated with the demonstration case managers nor reinforced the advice that the case managers gave to the patients; (2) guidelines on the frequency and content of contacts with patients and the degree to which these contacts should vary with the patients' characteristics and acuity levels were too general, and no followup was conducted to assess the causes and avoidability of the patients' adverse outcomes; (3) case managers lacked sufficient background in case management; and (4) projects lacked both a financial motivation to reduce Medicare spending and interim feedback on their performance in the aggregate.

The Balanced Budget Act of 1997 included further directives to study Medicare FFS reform alternatives. CMS contracted with Mathematica Policy Research, Inc. (MPR) to evaluate best practices of coordinated care, with the goal of recommending a design for a new demonstration that would test whether the best practices that have been used in managed care, commercial settings, or academic medical centers can generate the same types of savings and improved

outcomes in a Medicare FFS setting. After using various methods to identify as many successful programs as possible, Chen et al. (2000) conducted semistructured interviews with senior program staff of a select subset of these programs. The interviews obtained information about program features and elicited the staffs' opinions about the causes of their program's success or failure in reducing the need for hospitalizations.

That evaluation of best practices in coordinated care concluded that there is no optimal approach to care coordination. Successful care coordination programs varied widely in the types of interventions used, largely reflecting the various characteristics and needs of targeted patients and the structural characteristics of the organizations implementing the programs. However, most of the successful programs had several features in common, namely (1) a focus on well-developed care planning and patient education, (2) strong patient–case manager relationships, (3) a proactive emphasis on preventing health problems, (4) incorporation of evidence-based intervention guidelines, and (5) having experienced nurses serve as care coordinators. The study also identified some approaches to performing the three basic functions of care coordination (assessment and care planning, implementation and delivery, and reassessment and adjustment) that were common to a number of the successful programs. In addition, the report noted that developing an effective care coordination program takes several years.

2. The MCCD Demonstration

In July 2000, CMS issued a Request for Proposals (RFP) soliciting organizations to participate in the MCCD project, a demonstration mandated by the Balanced Budget Act of 1997. Applicants were expected to have experience operating a disease management or case management program, and to present some evidence that they had been able to reduce hospitalizations or costs. CMS took this approach to maximize the potential for showing, in a

time-limited demonstration, that a successful care coordination program could be adapted effectively to a Medicare FFS environment and population.

Of 58 submitted proposals, 15 were selected as demonstration sites. The 15 demonstration programs all serve chronically ill Medicare beneficiaries but target different diseases and vary widely in their interventions. The goals of the demonstration evaluation are to (1) provide CMS with unbiased estimates of the ability of the 15 demonstration sites to provide better and more cost-effective care for chronically ill Medicare beneficiaries; (2) assess the extent to which the effectiveness of care coordination depends on patient and program characteristics; and (3) provide guidance on the feasibility, desirability, and possible structure of a Medicare coordinated care benefit.

The MCCD programs are authorized to operate for four full years, and to enroll new patients through the 42nd month. During this period, programs are paid a capitated rate per month for each patient who is enrolled in the treatment group until the patient dies or disenrolls. The rates vary from $50 to $437 across the 15 programs.[4] In return for the capitation payment, programs must provide the intervention that was described in their approved operational protocol established with CMS.

The programs started enrolling patients between April and September 2002, after receiving approval of the waiver package from the Office of Management and Budget (OMB). Six program sites started enrolling in April, five started in June, one did so in July, two began in August, and one began in September. In each program site, Medicare beneficiaries who expressed an interest in participating in the demonstration and who met the program's eligibility

[4]Five programs have multiple rates. The rate that is applicable for a particular patient depends on his or her diagnosis, acuity level, or length of time in the program.

criteria were randomly assigned (by MPR) to either the treatment group, which received the intervention as well as their normal Medicare benefits, or to the control group, which received only their normal Medicare benefits. We compare these programs in the remainder of this report. Appendix A provides profiles of the 15 programs by briefly describing some of the key features of each one.

3. Other CMS Initiatives to Improve Outcomes for People with Chronic Illnesses

The MCCD is only one of several efforts that CMS is pursuing to make disease management and other types of care coordination available to Medicare FFS beneficiaries. The Benefits Improvement and Protection Act of 2000 mandated a demonstration to test disease management programs with a prescription drug benefit and guaranteed net savings to Medicare. That demonstration is nearing implementation, with three demonstration programs preparing to begin enrollment by early 2004. Other single-site disease management demonstration programs are under development. CMS also has issued a request for proposals for a capitated disease management program in which participating programs will be at risk for all Medicare-covered services, and is developing a request for proposals for a population-based program in which the participating programs will have responsibility for serving *all* Medicare beneficiaries in their defined service areas who have the targeted diagnoses.

The findings from the MCCD evaluation should provide useful guidance to these new demonstration efforts on effective practices in care coordination. Comparison across the different demonstrations should help to identify the effects of target population, organization type, scale, incentives, drug coverage, and alternative approaches to recruitment and care coordination.

C. PURPOSE OF AND METHODOLOGY FOR THIS REPORT

This report is a synthesis of preliminary findings from the first year of the MCCD. Although the goals of the study are to estimate the impacts of each of the programs and to assess which program features appear to be associated with program services, it is premature to estimate any impacts at this time. At the time that the analysis for this report was begun (in the summer of 2003), the programs had been operating for only 9 to 14 months, so few enrollees had much exposure to the programs, and Medicare claims data were available only on those enrolled during the first few months of program intake. Thus, this report focuses mainly on describing how the programs were designed, how the programs were implemented, and the characteristics of their enrollees. However, we also present some important, but preliminary, findings on patient and physician satisfaction.

Data are drawn from a wide range of sources. The number of programs on which a given component of this analysis is based depends on when the programs began enrolling, and on the data available at the time that the analysis files were prepared. For example, the implementation analysis and the analysis of patient survey data are based only on the six programs that began enrolling in April 2002. Both the analysis of program participants and the analysis of the physician survey include enrollees from the 12 programs that began enrolling in April or June.

1. Implementation Analysis

The evaluation's implementation analysis is based on information gathered during telephone interviews with program staff conducted approximately three months after the staff's program began enrolling patients, and on in-person interviews conducted approximately six months after the telephone interviews. The analysis also is based on MPR staff review of written materials that each program provided, including the program's proposal to CMS, its operational protocol, materials given to patients and physicians, and forms used in its operation. One of three MPR

implementation team members conducted both the telephone interviews and the in-person interviews for a site, using semistructured protocols. The interviews covered the following topics: organization and staffing, targeting and patient identification, program goals, care coordination activities (such as assessment, patient education, and service arrangement), physicians' attitudes about both the program and program interventions with physicians, quality management, record keeping and reporting, and financial monitoring. Use of the protocols ensured that each interviewer collected as consistent a set of information for each program as possible, while allowing the interviewer to explore issues of specific importance to each program. The structure of the protocols makes synthesizing findings across programs more efficient.

The implementation analysis also includes an examination of program data on care coordinators' contacts with patients, patient disenrollment, and services that the programs purchased for patients during their first six months of operations. These data, collected by the 15 programs specifically for the evaluation, enable us to assess how quickly patients receive their initial assessment, the average number of care coordinators' contacts with their patients, and the purpose or content of these contacts (for example, for assessment, monitoring, or education). However, comparison across programs should be interpreted cautiously. Although all 15 generally followed MPR guidelines designed to ensure comparability of data collection across programs, they differ somewhat in how they classify some activities.

2. Participation Analysis

We use Medicare claims and eligibility data to estimate the number of Medicare beneficiaries in each program's service area who potentially were eligible for the program and the percentage who actually participated. Beneficiaries are identified as eligible for a particular program if, for any month during the program's first six months of operations, they (1) lived in

the program's catchment area, (2) were enrolled in Medicare Parts A and B, (3) had Medicare as their primary payer, (4) were not in a Medicare managed care plan (Medicare+Choice plan), (5) met the program's target diagnosis and utilization requirements, and (6) did not have any of the programs' exclusion criteria (for example, end-stage renal disease or terminal cancer).

This definition of eligibility is flawed for many of the program sites, because some of the programs imposed additional restrictions at intake that we could not take into account when trying to identify eligible beneficiaries by using the claims data (such as not being deaf, having a telephone, having at least a fourth grade reading level, or exceeding some disease-severity threshold). Furthermore, the proportions who actually participated also are heavily influenced by the scope and intensity of the programs' recruiting efforts and referral sources. For example, many programs relied primarily on their own data systems or on those of a few affiliated hospitals or physician groups to identify potentially eligible patients, and therefore would not be able to find or enroll many of the beneficiaries in the catchment area that we identify from the claims data as being eligible. Nonetheless, the proportions are useful as a rough gauge of program penetration among Medicare beneficiaries with specific illnesses.

We also use Medicare claims and enrollment data to assess whether the programs enrolled a representative mix of eligible beneficiaries. We conduct that analysis by comparing the demographic characteristics, diagnoses, and utilization histories of the eligible nonparticipants with those of participants. The analysis compares service use and cost measures for the 12-month period preceding enrollment for the enrollees and the service use and cost measures for a comparable period for eligible nonparticipants (the 12 months beginning 9 months before program startup and ending 3 months after startup). In addition, we compare the average costs for the eligible nonparticipants with MPR's projected average costs for the target population that were presented in the OMB waiver package for the demonstration.

3. Patient Characteristics and Experiences

We also present preliminary findings from survey data collected on 1,695 patients during the first two months of interviewing (May 16, 2003, through July 9, 2003). The patient survey for each program is being conducted in two waves—one wave approximately 12 months after the program's startup (May through September 2003), and the second about 6 months later (October 2003 through April 2004). The sample for the first wave was drawn from beneficiaries who enrolled during the first six months of program operations, so that they would have 7 to 12 months of experience with the program by the time we interviewed them. (The second wave will survey beneficiaries enrolling during the 7th through 12th months after program startup and will be pooled with the first cohort for the future impact analysis.) For the analysis presented here, we have data only on the earliest enrollees from the first wave of the survey.

The interviews were conducted by telephone, using computer-assisted software. The patient survey instruments contain a set of core questions that were asked of all interviewees, regardless of diagnosis or condition, and a series of condition- or disease-specific modules. Each patient completed the one disease-specific module that best matched his or her primary health problem, as assessed by the program's intake staff at the time of enrollment. (A "generic" module was administered to patients who had no dominant chronic illness.) The survey collected data on patient demographics, primary language, well-being, health status, satisfaction with care, health-related behaviors, adherence to medication regimens, and knowledge of condition.

For programs with relatively low enrollment, we attempted to interview all of their patients; however, for the six programs with the largest enrollments, we drew a random sample of patients to interview. Our combined target sample size in each demonstration program for the two survey waves combined is 618 completed interviews (309 each for the treatment and control groups). As we discuss, most of the sites enrolled fewer than 618 patients during their first year of

operations. For each of the six sites that enrolled more than 686 patients during the first year (the number required to yield the target sample size of 618 completed interviews, assuming a 90 percent response rate), we selected a random sample of 686 enrollees whom we attempted to interview. For programs enrolling fewer than 686 patients, we attempted to complete interviews with all patients. However, we did not conduct any surveys in the three smallest programs, each of which enrolled fewer than 100 patients during its first year of operations.

The sample sizes available for individual sites for this report were too small to support site-specific analysis. Given the time frame for this report, only data collected during the first two months of survey operations could be included in this analysis. This restriction also means that the survey sample used here includes only patients enrolled in the first group of programs to start enrolling patients (the six programs that started enrolling in April 2002). Thus, the results are not representative of all programs, and they are dominated by the experiences of the two early starters with the largest enrollments. Future analyses will be based on data for the full survey sample.

4. Physician Characteristics and Experiences

We provide some preliminary findings from data gathered in interviews with the treatment group patients' primary care physicians. The purpose of the physician survey is to collect information on physicians' reactions to, and satisfaction with, the care coordination programs. As with the patient survey, we will conduct the physician survey in two waves, each intended to yield completed surveys on a sample of 25 physicians from each program (or on however many can be obtained, if the patients in a particular program identify fewer than 25 physicians). The first wave of the survey began on June 5, 2003; the sample for that wave was drawn from the physicians identified by treatment group patients who enrolled during the first nine months after program startup. (At the time of enrollment, patients are asked to name the physician whom they

see most often for care for their targeted health problems.) The second-wave sample will be drawn from physicians identified by patients enrolling between months 10 and 20 after program startup and will be conducted 22 months after program startup. We select samples of 37 physicians for each wave in order to obtain 25 completed interviews (assuming a 70 percent completion rate).[5] If the treatment group members enrolling in the program during the sampling period identify fewer than 37 different primary care physicians, we attempt to interview all the physicians identified by those enrollees.

For this report, data are available only on the 171 physicians who were selected for the first wave and who were interviewed during the first two months of fielding (June 5, 2003, through August 4, 2003). Future analyses will be based on data on the full sample of physicians from both waves, which is expected to total roughly 800 physicians.

D. THE REMAINDER OF THIS REPORT

In Chapter II, we present information on the target population and recruitment strategies for all 15 programs, and data on program participation rates and characteristics of participants for the 11 programs that had been in operation for at least one year as of June 2003. Chapter III compares six programs that began enrolling in April 2002 on the ways in which various program components are being implemented. Chapter IV presents results from the survey data on the satisfaction of physicians and patients interviewed for this study during the first two months of fielding. Chapter V synthesizes the lessons from this early study, describes the content of future reports about this evaluation, and presents a schedule for the reports. An appendix describes the individual programs in more detail.

[5]The probability of a physician being sampled is proportional to the number of treatment group members in his or her practice.

II. WHICH ORGANIZATIONS AND PATIENTS ARE PARTICIPATING?

The Medicare Coordinated Care Demonstration (MCCD) is evaluating 15 programs hosted by a diverse array of organizations from across the country. The programs have targeted beneficiaries living with a variety of chronic illnesses and have tailored their approaches to delivering care coordination both to those diagnoses and to their own visions of how best to improve patient care.

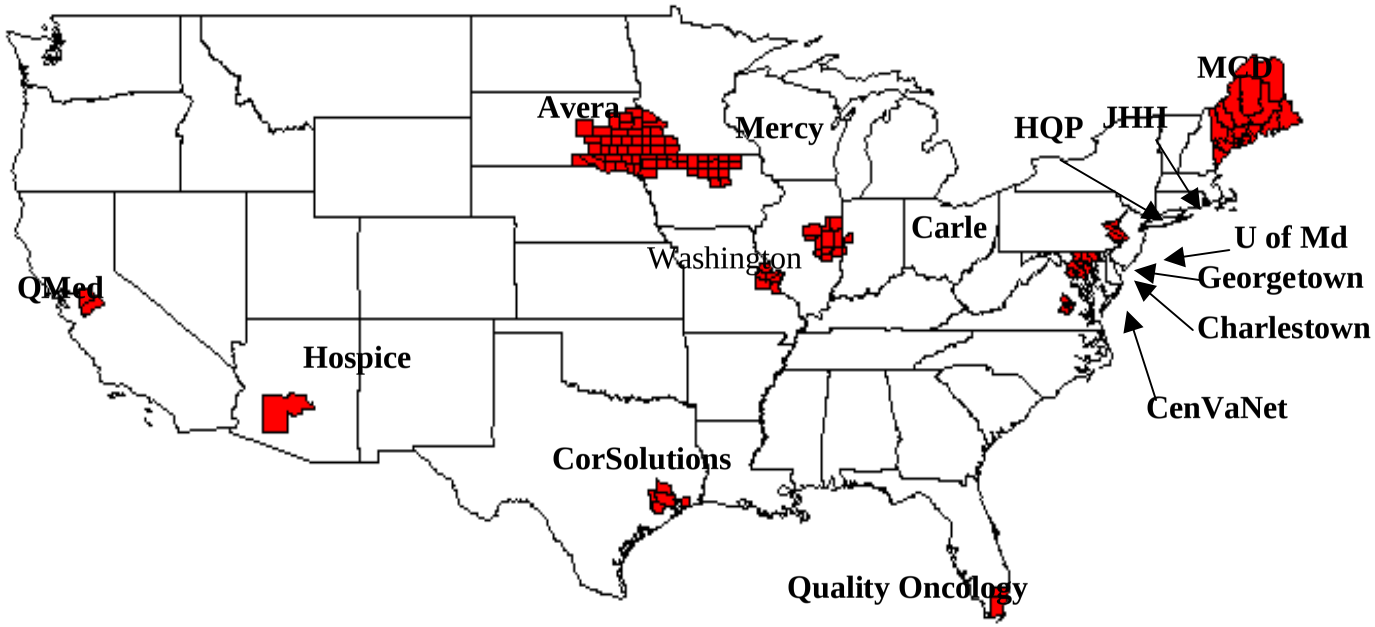
As of the time of our analysis, the programs served patients in 16 states and in the District of Columbia, from Maine to Arizona, and from northern California to south Florida (Figure II.1). Four programs served patients in rural areas; the other 11 served patients in cities and suburbs. The program hosts consisted of five commercial vendors, three hospitals, three academic medical centers, one integrated delivery system, a hospice, a retirement community, and a long-term care facility (Table II.1).

Six of the 15 programs targeted only a single condition; 4 of them targeted congestive heart failure (CHF), 1 targeted coronary artery disease, and 1 targeted cancer (see Table II.1). Another program targeted several heart conditions. Each of the eight other programs targeted several diagnoses. Three of the eight (Jewish Home and Hospital, Mercy, and Washington University) cast particularly wide nets by targeting many diagnoses or by targeting beneficiaries who were frail or otherwise considered to be at high risk for hospitalization.

In this chapter, we first provide an overview of the 15 programs that chose to participate. We then describe how they recruited beneficiaries during the first year of operations, the number of patients who enrolled, and some key characteristics of these patients. We conclude by comparing patients who enrolled in the programs with eligible beneficiaries who did not enroll.

Figure II.1

The Medicare Coordinated Care Demonstration Sites, Catchment Areas as of Summer 2002



Hospice = Hospice of the Valley; HQP = Health Quality Partners; JHH = Jewish Home and Hospital Lifecare System; MCD = Medical Care Development; U of Md = University of Maryland.

TABLE II.1

PROGRAMS PARTICIPATING IN THE EVALUATION

Host Organization	Organization Type	Service Area	Targeted Diagnoses
Avera Research Institute/Avera McKennan Hospital and University Health Center	Hospital	49 counties in South Dakota and 22 contiguous counties in Minnesota, Nebraska, and Iowa	CHF
Carle Foundation	Integrated delivery system	11 counties in east central Illinois and 2 counties in west central Indiana	Heart conditions Diabetes Chronic lung disease
CenVaNet	Provider of care coordination services owned by hospitals and physicians	Richmond, Virginia, metropolitan area	Heart conditions Diabetes Chronic lung disease Cerebrovascular disease
Charlestown Retirement Community	Part of Erickson Retirement Communities	3 retirement communities in the Baltimore, Maryland, metropolitan area	Heart conditions Diabetes COPD
CorSolutions	Provider of disease management services	Harris County (Houston), Texas	CHF
Georgetown University Medical School	Academic institution in partnership with Medstar, owner of Georgetown University Hospital and Washington Hospital Center	Washington, DC, and parts of Maryland and Virginia	CHF
Health Quality Partners	Provider of quality improvement services	Eastern Pennsylvania	Heart conditions Diabetes Asthma Moderate to severe hyperlipidemia or hypertension
Hospice of the Valley	Hospice	Maricopa County, Arizona (greater Phoenix)	CHF COPD Cancer Neurological conditions

TABLE II.1 *(continued)*

Host Organization	Organization Type	Service Area	Targeted Diagnoses
Jewish Home and Hospital Lifecare System	Long-term care provider, in partnership with the medical practices of St. Luke's and Mt. Sinai hospitals as referral sources	Manhattan, New York City	Heart conditions Diabetes Chronic lung disease Cancer Liver disease Stroke or other cerebrovascular disease Psychotic disorder Major depressive or anxiety disorder Alzheimer's or other cognitive impairment
Medical Care Development	Consortium of 17 Maine hospitals hosted by a health services research organization	Rural areas of Maine	Heart conditions
Mercy Medical Center/North Iowa	Hospital	Rural areas of Iowa	CHF Chronic lung disease Liver disease Stroke Vascular disease Renal failure
QMed	Provider of disease management services	2 counties in northern California	CAD
Quality Oncology, Inc.	Provider of disease management services	Broward county, Florida	Cancer
University of Maryland Medical School	Academic institution	Baltimore, Maryland, metropolitan area	CHF
Washington University School of Medicine	Academic institution in partnership with American Healthways, a disease management services provider	St. Louis, Missouri, metropolitan area	No specific diagnoses targeted[a]

Note: Heart conditions may include congestive heart failure (CHF); coronary artery disease (CAD); atrial fibrillation; and ischemic, hypertensive, or other heart diseases. Chronic lung disease includes asthma and chronic obstructive pulmonary disease (COPD). Neurological conditions include stroke, Alzheimer's disease, Parkinson's disease, and amyotrophic lateral sclerosis. See the program profiles in Appendix A for the specific diagnoses included by each program.

[a]Washington University uses an algorithm developed by its demonstration partner, American Healthways, to target Medicare beneficiaries who are likely to become clinically unstable and to require hospitalization during the next 12 months.

A. PROGRAM OVERVIEW USING A THREE-DIMENSIONAL TYPOLOGY

The recent rapid growth in care coordination and disease management initiatives for people with chronic illnesses has yielded a confusing array of programs. Some programs rely on monitoring and reminder devices; some educate patients about self-management; others focus on improving physician practice; and still others intervene at multiple levels, from physician practice and patient behavior to coordination of providers and services. One of the aims of the MCCD evaluation is to develop a method of classifying the wide variety of programs by using readily observed program features, and, eventually, to relate this classification to program impacts. We have started with a simple framework that continues to evolve as we learn more from the demonstration programs. The current framework classifies a program based on three critical program features: (1) the program's major approaches to improving patient health and reducing health care costs (namely, improving patient adherence to treatment recommendations, improving provider practice, improving communication and coordination among providers, and increasing access to support services); (2) the capacity of the organization hosting the demonstration program to integrate the program's efforts with those of key providers; and (3) whether the program focuses its interventions primarily on its specific target conditions or on problems faced by chronically ill and frail patients more generally. In this report we simply classify programs as to whether they had certain features; later reports will assess how well the features were implemented and whether implementation was associated with program effectiveness.

1. Major Program Approaches

Care coordination is predicated on the belief that the failure of patients and physicians to properly manage chronic illnesses results in uncontrolled symptoms and acute exacerbations that could have been avoided, but instead, lead to expensive treatment. All of the MCCD programs

shared the broad goal of improving patient health as a means of reducing the use of emergency rooms, inpatient hospital services, and other acute care services. The programs varied as to which of four basic approaches they adopted to achieve that goal (Table II.2).

a. Improving Patient Adherence

All but two programs sought to improve patient adherence through patient education (by teaching patients about disease management directly or by sending them to receive education outside the program). University of Maryland focused on improving medical management, rather than patient adherence, and relies on feedback from its CHF patients' home monitoring devices to support this approach. QMed sought to improve patient adherence, but rather than rely on patient education, this program relied primarily on feeding back readings from monitoring devices to the patients' physicians, who, in turn, were expected to encourage patients to adhere to care regimens.

b. Improving Communication and Coordination

All but one of the programs sought to improve communication and coordination across providers (specifically, by seeking to ensure that primary and specialty physicians shared relevant patient information in a timely way; resolved issues of polypharmacy or conflicting advice from physicians; ensured that necessary tests were conducted at intervals consistent with national guidelines; and followed up on and identified causes of adverse patient events, such as emergency room visits). Most of the programs taking this approach (11 of the 14) sought primarily to teach patients to communicate better with physicians, and to schedule necessary tests and other types of care on their own. Their patient education may have involved coaching the patients on the types of questions to ask or helping them to prepare lists of questions for what

TABLE II.2

PROGRAM APPROACHES

Program	Improve Patient Adherence	Improve Communication/ Coordination (Strategy)	Improve Provider Practice (Aspect)	Increase Access to Support Services
Avera	Yes	Yes (Teach patients)	Yes (Clinical practice)	Yes
Carle	Yes	Yes (Teach patients)	Yes (Clinical practice)	Yes
CenVaNet	Yes	Yes (Teach patients)	No	Yes
Charlestown	Yes	Yes (Care coordinators intervene directly)	No	Yes
CorSolutions	Yes	Yes (Teach patients)	Yes (Clinical practice)	Yes
Georgetown	Yes	Yes (Teach patients)	Yes (Accept care coordination)	Yes
Health Quality Partners	Yes	Yes (Teach patients)	Yes (Accept care coordination)	Yes
Hospice of the Valley	Yes	Yes (Teach patients)	No	Yes
Jewish Home and Hospital	Yes	Yes (Teach patients)	No	Yes
Medical Care Development	Yes	Yes (Teach patients)	No	Yes
Mercy	Yes	Yes (Teach patients)	Yes (Accept care coordination)	Yes
QMed	Yes	Yes (Care coordinators intervene directly)	Yes (Clinical practice)	Yes
Quality Oncology	Yes	Yes (Teach patients, care coordinators intervene directly)	Yes (Clinical practice)	Yes
University of Maryland[a]	Limited	No	No	No

TABLE II.2 *(continued)*

Program	Improve Patient Adherence	Improve Communication/ Coordination (Strategy)	Improve Provider Practice (Aspect)	Increase Access to Support Services
Washington University	Yes	Yes (Teach patients)	No	Yes

Notes: Improve Communication and Coordination: Programs that primarily teach patients to communicate better and to coordinate their own care do so through teaching, coaching, and giving patients question lists to be used during physician visits. Care coordinators for programs that primarily teach patients also will intervene directly with providers, if necessary.

Improve Provider Practice: Programs are described as seeking to improve clinical practice if they provide physicians with guidelines or reports that show patient deviations from guidelines or facilitate group discussions about guidelines. Programs that described themselves as trying to change physician practice on a patient-by-patient basis were not categorized in this way unless they also had an approach to changing clinical practice more broadly.

Increase access to support services: Programs are included in this category if they pay for medications, pay for other goods and services, or refer patients to or arrange for goods and services. Although almost all the programs took this approach, it was not usually a primary focus of their interventions.

[a]The University of Maryland's primary program goal is to improve clinical outcomes through its own medical management of patients. Its objectives for improving patient adherence are limited to improving monitoring of weight, blood pressure, and heart rate, using a home monitoring device.

have become increasingly short physician visits. In addition, the programs typically taught patients to recognize when physicians should be contacted concerning worsening symptoms, to understand the types of preventive care that are necessary, and to be aware of the proper schedule for preventive care. Despite the programs' focus on teaching patients to communicate better and to coordinate their own care, the programs' care coordinators intervened on behalf of patients who were too frail and had no able caregivers, or who needed an advocate for any reason.

Two programs (Charlestown and QMed) primarily had care coordinators intervene with physicians on behalf of patients. Charlestown had its care coordinators intervene directly with physicians because it seemed more efficient to do so, given that the care coordinators and physicians had established close working relationships before the demonstration began. QMed's care coordinators worked primarily with physicians (rather than with patients) to ensure that necessary tests were ordered, and to resolve any problems that patients had adhering to medication regimens. Less frequently, they taught patients to communicate more effectively with their physicians.

Quality Oncology appears to have adopted both approaches, with the specific communication topic determining which approach was used. Care coordinators taught patients how and when to report to their physicians about pain and side effects of their cancer treatments, and to ask physicians how to deal with these problems. They also encouraged patients to raise questions with their physicians about prognosis and end-of-life care. In the case of more technical clinical issues, however, the care coordinators contacted the physicians directly (for example, to discuss recommendations for chemotherapy, radiation therapy, or follow-up scans, and to inform the physicians about urgent patient symptoms).

c. Improving Physician Practice

Most of the programs tried to improve physician practice in some way. However, only five programs adopted a structured approach to improve the overall clinical practice patterns of physicians; these programs provided physicians with regularly updated guidelines for the targeted diagnoses, produced reports for the physicians that showed deviations from guidelines for program patients, or facilitated group discussions about the guidelines. During the interviews with the staffs of the 15 programs, the following reasons were given to explain why only 5 programs have taken this approach: (1) the programs have little leverage over physicians, (2) physicians have no time to participate in additional education efforts, and (3) most physicians who serve program patients already are familiar with and largely conform to guidelines. (The latter explanation may stem from the fact that only relatively high-performing organizations applied to become demonstration sites and were then selected in a competitive process.)

Several other programs indicated that they had more modest goals concerning physician practice improvement. Three programs reported that they were trying to improve physician practice by increasing the physicians' acceptance of care coordination (specifically, by helping physicians understand that care coordinators can help them to take better care of some of the most difficult and time-consuming patients). Other programs described themselves as trying to change physicians' clinical practice on a patient-by-patient basis (for example, improving physicians' prescribing practice by informing physicians that particular patients have not been given an optimal drug regimen; not shown in Table II.2).

d. Increasing Access to Support Services

Programs also sought to improve patient health by increasing patients' access to support services that are not covered by Medicare (such as home care; transportation; certain equipment

and supplies; and disease-specific, diet, or smoking-cessation support groups), or by helping patients to pay for prescription drugs. Although none of the programs considered improving access to services a primary focus of their efforts, they recognized that the availability of support services can be crucial for at least some of their patients. Thus, all but one program could refer patients to these services, and all but three had limited funds to pay for goods and services or provided them directly. (In fact, during the first six months of operation, care coordinators arranged for personal care, meals, or transportation for fewer than 10 percent of their patients, and programs purchased such services for an even smaller percentage.)

Access to prescription drugs is particularly important to chronic disease management, as even beneficiaries with drug coverage may have needs that exceed their coverage. Three programs provided limited funds to help patients to close drug coverage gaps. In addition, half of CorSolutions' treatment group was randomly assigned to be eligible for coverage of all prescription medications if a patient in that group required it. (Thus far, few have received coverage because their incomes exceed the program's eligibility threshold to qualify for such assistance.)

2. Capacity for Integration with Providers

Having the structures in place to integrate program efforts with those of patients' physicians and other providers is important, as the integration of these efforts facilitates communication between physicians and care coordinators and fosters the establishment of trusting professional relationships. Trusting relationships give care coordinators credibility in the eyes of the physicians and allow physicians to feel comfortable sharing important patient information with the care coordinators, asking care coordinators to intervene with patients when necessary, and responding to issues that the care coordinators raise. The following program features may promote integration between a program and its physicians:

- Previous Experience with Care Coordination Programs Involving the Same Physicians or Organizational Ties to Them. Physicians who have had positive experiences with similar programs are likely to be much less suspicious of the program and more willing to cooperate with it. Organizational links between the program and physicians, such as a shared employer (for example, if the host is a medical center), increase the likelihood that physicians will be familiar with program staff, can lead to a common vision of patient care, and may give the program some leverage over physician behavior (for example, in encouraging physicians to refer patients or to cooperate with care coordinators).

- ***Use of Physician Opinion Leaders or a Physician Advisory Board.*** These approaches promote active physician involvement with the program. A physician advisory board also can give physicians a sense of "ownership" of the program.

- ***Co-Locating Care Coordinators with Physicians or Assigning All of a Physician's Patients to a Particular Care Coordinator.*** These methods help coordinators and physicians to become familiar with each other, and give these staff the opportunity to talk about patient care frequently and informally.

- ***Provision of Regular Meetings or Reports.*** More-formal mechanisms, such as holding regular meetings of care coordinators and physicians to discuss patient care or regularly sending physicians reports throughout the year about program patients, build ties and ensure that these staff will interact to some extent. (Compensating physicians for meeting attendance or report review is likely to increase their participation.)

Thirteen of the 15 programs had two or more of these features (not shown). Three programs had all four, suggesting the potential for highly integrated interventions. Another program (Jewish Home and Hospital) had just one: its medical directors were also the directors of the physician practices from which the program recruited patients. One program (Hospice of the Valley) had none of these features. It is likely that, compared with the other programs in the demonstration, the latter two programs will have a much harder time integrating their efforts with those of their patients' physicians, although such integration is possible (for example, if care coordinators are highly skilled in and have the time to devote to building relationships with physicians on their own).

3. Degree of Focus on Target Conditions

The final dimension of the three-part typology classifies programs according to the extent to which they focus their efforts on the problems associated with their target diagnoses. This dimension of the typology categorizes program focus as follows: (1) primarily on targeted diseases; (2) on targeted diseases and on comorbidities and psychosocial problems (such as depression, social isolation, or unmet needs for support services or goods to ensure a safe, healthy living environment); or (3) primarily on psychosocial problems faced by patients who are chronically ill and frail, with less attention given to the management of specific diseases. Our analysis showed that, rather than falling neatly into one of these three categories, the foci of the 15 demonstration programs could be placed on a continuum. Most programs provided condition-specific disease management, helped patients to cope with comorbid conditions, and, to varying degrees, addressed psychosocial problems. A few programs fell toward the extremes of the continuum. Thus, three programs (QMed, Quality Oncology, and University of Maryland) focused their efforts primarily on patients' target diagnoses. So, too, did Health Quality Partners, in its work with its low-risk patients. By contrast, Jewish Home and Hospital focused primarily on reducing social isolation, providing little condition-specific education for its patients (so that its more limited capacity to integrate with physicians may be less important).

B. PATIENT IDENTIFICATION AND ENROLLMENT

The programs had wide-ranging goals for enrolling beneficiaries during the first year of operations: from 480 to 800 enrollees (split between treatment and control groups) for nine

programs, to 2,000 or more for three others (Table II.3).[6] Half the programs intended to enroll most of their patients (roughly 75 percent or more) during their first year. The others extended enrollment over the full demonstration period.

1. Patient Identification

Programs generally adopted one of two primary approaches to identifying beneficiaries who would be asked to participate: (1) obtaining lists of prospective enrollees from hospitals or health care networks (9 programs), or (2) recruiting physicians who then referred patients to a program (6 programs; see Table II.3). Programs that had hospitals or health care systems as their host organizations generally identified potentially eligible beneficiaries primarily from lists of host-system patients, using automated screening along broad program eligibility criteria, such as diagnosis and Medicare coverage. Six such programs were Avera, Carle, Georgetown, Mercy, University of Maryland, and Washington University. Rather than screening on particular diagnoses, Washington University partnered with a disease management vendor and used the vendor's proprietary algorithm to identify high-risk patients for the program from the program's physician network records. Three of the six programs also recruited other health systems to provide lists of their patients. Georgetown and University of Maryland did this during their first year of operations; Carle started recruiting hospitals and physician practices outside its system toward the end of its first year. Of the three other programs that recruited from lists provided by hospitals or health systems, one was a retirement community that included its own primary care physicians in the program, and one recruited from a few local hospitals and a large hospitalist

[6]One of the three programs (CorSolutions) has a treatment group with two arms: one that provides, in addition to care coordination, a prescription drug benefit to patients who need the benefit, and one that provides care coordination only. Each arm is to enroll 500 patients. The program's control group will have 750 patients.

TABLE II.3

TARGET ENROLLMENT VERSUS ACTUAL ENROLLMENT AFTER ONE YEAR

Host Organization (Start Date)	Target Enrollment[a]	Actual Enrollment After One Year[b]	Primary Method to Identify Potential Enrollees	Most Likely Reason for Success or Shortfall[c]
Avera (6/4/02)	Year 1: 788 Full demonstration: 1,268	318	Generates list from host system	Shortfall: Not enough patients meeting service use criterion and high patient refusal rate
Carle (4/19/02)	Year 1: 2,256 Full demonstration: 3,036	2,283	Generates list from host system[d]	Success: Physicians promoted the program
CenVaNet (4/8/02)	Year 1: 1,048 Full demonstration: 1,228	1,074	Recruits physicians from host network	Success: Time spent marketing program to physicians prior to start
Charlestown (4/29/02)	Year 1: 684 Full demonstration: 792	430	Generates list from host system	Shortfall: Not enough patients meeting service use criterion
CorSolutions (6/18/02)	Year 1: 1,750[e] Full demonstration: 2,392	671	Recruits physicians	Shortfall: Lack of physician support
Georgetown (6/5/02)	Year 1: 730 Full demonstration: 2,050	108	Generates lists from host and other systems	Shortfall: Lack of physician support and high patient refusal rate
Health Quality Partners (4/30/02)	Year 1: 738 Full demonstration: 2,140	498	Recruits physicians	Shortfall: Lack of resources to recruit and high patient refusal rate
Hospice of the Valley (8/15/02)	Year 1: 624 Full demonstration: 2,184	460	Generates lists from other systems Recruits physicians	Shortfall: High patient refusal rate
Jewish Home and Hospital (6/17/02)	Year 1: 730 Full demonstration: 730	543	Chart review for two large geriatric group practices affiliated with program	Shortfall: Lack of resources to recruit
Medical Care Development (4/17/02)	Year 1: 1,048 Full demonstration: 2,436	393	Generates lists from participating hospitals	Shortfall: Lack of resources to recruit and lack of physician support
Mercy (4/19/02)	Year 1: 482 Full demonstration: 1,214	627	Generates list from host system	Success: Physician support based on previous work with program staff, access to comprehensive data system to identify patients

TABLE II.3 *(continued)*

Host Organization (Start Date)	Target Enrollment[a]	Actual Enrollment After One Year[b]	Primary Method to Identify Potential Enrollees	Most Likely Reason for Success or Shortfall[c]
QMed (7/12/02)	Year 1: 782 Full demonstration: 1,142	1,404	Recruits physicians	Success: Physician support based on previous work with host system
Quality Oncology (9/18/02)	Year 1: 2,132 Full demonstration: 2,852	63	Recruits physicians	Shortfall: Lack of physician support
University of Maryland (6/28/02)	Year 1: 678 Full demonstration: 678	58	Generate lists from host and other systems	Shortfall: Lack of physician support
Washington University (8/16/02)	Year 1: 2,000 Full demonstration: 2,000	1,425	Generate list from host system	Shortfall: High patient refusal rate

Note: Enrollment includes beneficiaries randomly assigned to both the treatment and control groups.

[a]Most of the enrollment targets for the 15 Medicare Coordinated Care Demonstration (MCCD) programs for year 1 and for the "full demonstration" period come from enrollment flows projected by the individual programs and incorporated into the Office of Management and Budget waiver package prepared by Mathematica Policy Research, Inc. (MPR). They include patients enrolled to replace treatment group attrition due to death or disenrollment.

The CorSolutions and Washington University waiver package targets were reduced by CMS to the numbers shown. CorSolutions has a treatment group with two arms: one that provides care coordination and a prescription drug benefit to patients who need it, and one that provides care coordination only. Each arm is to enroll 500 patients. Its control group will have 750 patients.

The "full demonstration" period is four years for the MCCD programs. Programs are permitted to enroll patients for the first three and one-half years of the demonstration but cannot enroll during the last six months.

[b]Actual enrollment figures for each program come from the MPR weekly enrollment report for the week that included the program's one-year anniversary. Actual enrollment includes beneficiaries who are living in the same household (such as spouses) but who are not included in the research sample (as the research sample could include only one enrolled beneficiary per household).

[c]Cited reasons were given by program staff.

[d]During year 1, almost all of Carle's patients were drawn from the Carle health system. However, late in that year, the program began developing referral arrangements with hospitals and physicians' groups outside the system. Subsequent enrollment years will reflect the fruits of those efforts.

group practice. The third (Medical Care Development), which partnered with 17 hospitals in Maine, identified potentially eligible beneficiaries while they were inpatients at one of the hospitals by reviewing admissions logs each day.

Most of the 9 programs that first identified patients from electronic lists subsequently contacted the identified patients' physicians to discuss the program. Some of those programs then asked the physicians for permission to contact their patients. Two programs that relied on electronic lists contacted patients on the lists directly, without first approaching the patients' physicians.

Eight of the 9 programs also welcomed direct physician referrals to the program and hoped that the numbers of these referrals would increase as the programs became better known. (The ninth program enrolled only recently discharged inpatients.) During their first year, however, the eight programs identified the majority of their potential enrollees through the automated review of patient databases.

Six programs enlisted physicians to refer patients. The five programs with care coordination service providers as hosts first recruited physicians who wished to have their patients participate in the demonstration and then worked with the physicians to generate lists of potentially eligible and appropriate patients. Rather than recruiting patients directly from its own care system, the sixth program (Jewish Home and Hospital) developed a partnership with two large geriatric practices prior to implementation.

All but 3 of the 15 programs introduced themselves to patients by sending letters signed by the patients' own physicians. (Washington University's letters were signed by the program's medical director.) Instead of sending letters, Hospice of the Valley and University of Maryland had their care coordinators telephone identified patients. (University of Maryland's care coordinator also introduced the program during in-person visits with hospitalized patients who

had been identified while they still were in the hospital.) The enrollment staff of the third program (Jewish Home and Hospital) first contacted patients while the patients were at the physician practice clinics that had identified them for the program. The clinics provided the program in advance with lists of patients scheduled for clinic visits. The program's enrollment coordinator then determined whether the patients were eligible for Medicare and examined their medical charts to verify that the patients had one of the program's target diagnoses. During the patients' clinic visit, their physicians briefly discussed the program and asked whether they would like to meet with the enrollment coordinator at that time.

Program staff of most of the 15 programs reported that physicians were too busy and visits too short for the physicians to promote the program to patients directly. Program staff handled most of the "marketing" of the program following the mailing of the introductory letter or during the introductory telephone or in-person encounter. The staff did report, however, that *if* patients specifically asked physicians whether they should participate, most physicians encouraged them to do so.

2. Enrollment After One Year

Four programs (Carle, CenVaNet, Mercy, and QMed) met or exceeded their enrollment goals for year 1 (Table II.3). The first three used centralized electronic patient databases to identify patients. They also had organizational links to and good relationships with the patients' physicians before the demonstration began, which likely led the physicians to enthusiastically encourage patients to enroll (if the patients asked for their advice on the subject). CenVaNet also marketed the program to network physicians in advance of its start. QMed had good relationships with area physicians and was considered a well-regarded disease management provider with long-standing ties to managed care plans in a service area with a high level of managed care penetration.

Six of the 11 programs that did not meet their enrollment targets for their first year of operations enrolled fewer than half the number of enrollees they had targeted. Program staff presented a variety of reasons for these shortfalls. Some noted that their programs had miscalculated the number of eligible beneficiaries in their service areas due to better-than-expected patient health. Five cited inadequate physician support for the program during the first year. In particular, a number of physicians with relatively larger practices in Quality Oncology's south Florida service area were hostile to the program because they had had negative experiences with the disease management vendor when it served as a managed care subcontractor. (Program staff reported that the vendor's focus on keeping the costs of chemotherapy agents low irritated physicians who were used to greater "price flexibility.") Other programs found refusal rates among eligible beneficiaries to be higher than anticipated; however, the high refusal rates probably were related, at least in part, to the absence of physician support. Finally, some programs that used care coordinators to conduct patient outreach and enrollment (as well as to provide patient care) noted that patient care demands reduced the time that these staff could spend recruiting. The program with the greatest number of participants (Carle) recognized this problem early in its first year; it resolved the problem by training other staff to conduct most of the recruitment activities. As was the case for some other programs, staff there also reported that most care coordinators were not particularly well-suited to undertake the marketing aspects of the program.

The experiences of the 15 programs during their first year of operations offer some lessons about patient recruitment. Physician support seemed to be the key to programs meeting their first-year enrollment goals. Staff from the four programs that met their goals acknowledged the importance of physician support that consisted of more than simply signing invitation letters. Staff of 8 of the 11 programs that did not meet their enrollment goals attributed the failure

primarily to either insufficient physician support or a high patient refusal rate. In addition, three of the four successful programs were able to use their host organizations' electronic patient databases to generate lists of potentially eligible patients. The same three programs also had established relatively broad eligibility criteria; by targeting a number of chronic conditions, the programs could be expected to produce larger pools of eligible patients than if they had targeted more narrowly. Finally, staff from all 15 programs noted that recruiting patients took more staff time than expected, and that recruitment made it difficult for care coordinators to balance their workloads.

3. Disenrollment During the First Six Months

During the first six months of operations, according to data that each program prepared for the evaluation, disenrollment of patients in the evaluation's treatment group was nonexistent to modest (Table II.4). Health Quality Partners and University of Maryland reported no disenrollees. Carle, CenVaNet, Hospice of the Valley, and Washington University reported that between 2 and 10 percent of patients who had enrolled subsequently were disenrolled either because they died or lost their eligibility (usually as a result of joining a managed care plan).

Very few patients *chose to leave* during the first six months, a reflection perhaps of both general satisfaction with the programs and the limited demands the programs placed on their enrollees. Hospice of the Valley and QMed had voluntary disenrollment rates of five percent and two percent, respectively. According to staff from those two programs, patients stated that they were leaving because they had changed their minds about participating (for example, because they had not realized how often they would have to interact with care coordinators) or because they believed they were doing well enough without the program. Disenrollment rates from the other programs were less than two percent.

These disenrollment rates must be viewed as highly preliminary because they cover a period during which patients had been enrolled for six months or less (about three months, on average). Disenrollment rates may increase the longer patients are in the programs.

C. PATIENT CHARACTERISTICS

The 10,972 patients enrolled in the treatment and control groups of the 15 demonstration programs through August 3, 2003, were somewhat older than the 38 million Medicare beneficiaries nationally—not surprising, given that older beneficiaries are more likely to have chronic illnesses, and that several programs chose to exclude beneficiaries who were younger than age 65. In 1999, 13 percent of all Medicare beneficiaries were younger than age 65, and 11 percent were age 85 or older (Centers for Medicare & Medicaid Services 2001). Overall, only 7 percent of patients enrolled in demonstration programs were younger than age 65; 15 percent were age 85 or older (Table II.5). However, the programs varied widely in the age distributions of their patients. For example, six program had no patients who were younger than age 65 and three had fewer than five percent who were that young, whereas more than one-fourth of Washington University's patients were younger than 65—far more than among beneficiaries nationally. Similarly, in four programs, 20 percent or more of the enrolled patients were age 85 or older; in one of the four (Charlestown), the proportion of patients in that age range was 45 percent.

Heart disease dominated the primary diagnoses of demonstration patients. More than one-fourth of all the patients enrolled in the programs had CHF. This high proportion stems from that fact that 13 out of 15 programs enrolled patients with CHF, and 4 of those enrolled *only* CHF patients. (By comparison, only nine percent of beneficiaries nationally had CHF in 1997, according to an analysis of data from the Centers for Medicare & Medicaid Services that Mathematica Policy Research, Inc. [MPR] conducted.) Other common primary diagnoses were

TABLE II.4

PROGRAM ENROLLMENT AND DISENROLLMENT
DURING THE FIRST SIX MONTHS OF OPERATIONS

Program	Number of Treatment Group Members Enrolled	Average Weeks of Enrollment	Number Who Disenrolled, by Reason			
			Patient Initiated	Died/Lost Eligibility	Completed Program	Other
Avera	57	11.0	0	2	0	2
Carle	663	15.3	5	11	0	0
CenVaNet	374	12.1	6	9	1	0
Charlestown	110	13.8	0	4	0	0
CorSolutions	99	8.7	1	6	0	6[a]
Georgetown	20	10.5	0	1	0	0
Health Quality Partners	104	10.2	0	0	0	0
Hospice of the Valley	108	12.5	5	11	0	0
Jewish Home and Hospital	155	9.8	1	1	0	0
Medical Care Development	58	11.2	1	3	0	0
Mercy	159	12.0	1	7	0	0
QMed	333	13.5	9	1	0	1
Quality Oncology	12	15.2	0	3	0	0
University of Maryland	16	13.1	0	0	0	0
Washington University	428	13.7	2	19	0	1
All Programs	**2,696**	**13.0**	**31**	**78**	**1**	**4**

Source: Program data covering the six months after the start of enrollment.

[a]CorSolutions uses "other" as an interim category for ambiguous responses, which are redefined after consultation with care coordinators.

TABLE II.5

DEMONSTRATION PATIENTS, BY AGE AND DIAGNOSIS

	Age				Diagnosis[a]				
Program	≤64	65-74	75-84	≥85	CAD	CHF	Diabetes	COPD	Other
Avera	0.0	30.8	48.1	21.1	0.0	100.0	0.0	0.0	0.0
Carle	1.1	46.5	40.4	12.0	18.3	2.3	38.7	12.3	28.4
CenVaNet	0.0	40.0	47.6	12.4	27.8	33.6	30.2	5.2	3.2
Charlestown	0.0	6.6	48.3	45.1	45.7	25.1	12.4	16.7	0.2
CorSolutions	13.4	38.1	35.2	13.4	1.1	98.9	0.0	0.0	0.0
Georgetown	0.0	31.1	53.8	15.1	0.0	98.3	0.8	0.0	0.0
Health Quality Partners	0.0	51.0	40.2	8.8	19.2	4.7	16.7	3.8	55.6
Hospice of the Valley	0.0	28.2	46.3	25.5	3.1	39.4	0.0	25.5	32.0
Jewish Home and Hospital	0.2	20.8	43.3	35.8	8.4	22.7	17.8	8.6	42.5
Medical Care Development	6.6	45.8	35.2	12.4	34.8	65.2	0.0	0.0	0.0
Mercy	4.2	31.4	46.3	18.0	0.3	42.3	0.0	30.6	26.8
QMed	6.9	47.3	40.9	4.9	100.0	0.0	0.0	0.0	0.0
Quality Oncology	10.5	40.4	40.4	8.8	0.0	0.0	0.0	0.0	100.0
University of Maryland	16.7	42.4	36.4	4.6	0.0	100.0	0.0	0.0	0.0
Washington University	27.9	35.4	27.4	9.3	0.0	5.9	1.5	0.4	92.3
Total	**6.5**	**38.3**	**40.4**	**14.8**	**23.9**	**29.0**	**13.3**	**7.5**	**26.3**

Source: Program intake data for 10,972 beneficiaries enrolled and randomly assigned as program and control patients through August 3, 2003.

CAD = coronary artery disease; CHF = congestive heart failure; COPD = chronic obstructive pulmonary disease.

[a]Primary diagnosis designated by beneficiary at enrollment.

coronary artery disease (24 percent of enrollees had that diagnosis), diabetes (13 percent of enrollees), and chronic obstructive pulmonary disease (8 percent). All of Quality Oncology's patients have been diagnosed with cancer, whereas only three of the other programs had *any* patients with cancer as their primary condition (not shown).

The primary diagnoses varied widely across programs as a direct result of the choices the programs made about which diagnoses to target. Two programs served sizable numbers of people with diabetes, and two drew at least one-fourth of their enrollments from patients with chronic lung disease. Finally, a high proportion of the enrollees of four programs were placed in the "other" category, indicating that no particular condition was known to be dominant at the time of enrollment, or that some health problem other than the ones listed, such as hypertension, was the dominant one for many of their enrollees.

Relatively few of the 1,463 treatment and control patients in the six programs for which we had early survey observations were nonwhite or Hispanic (Table II.6). Only roughly five percent of patients identified themselves as black, and only about two percent identified themselves as belonging to a racial group other than white or black; a small proportion identified themselves as belonging to two different racial groups. These proportions are somewhat below the proportions of Medicare beneficiaries nationally—nine percent of whom are black and six percent of whom identify themselves as members of some other race (Centers for Medicare & Medicaid Services 2001). Less than one percent of the enrollees identified themselves as Hispanic, as compared with seven percent for the Medicare population as a whole.[7]

[7]These differences were due mainly to the fact that several of the programs served areas with very few black or Hispanic Medicare beneficiaries. Other possible explanations for a low proportion of minorities (for example, having referral sources whose patient caseloads are predominantly white) will be explored in the next Report to Congress, when all of the sites will be examined and sample sizes are larger.

TABLE II.6

DEMOGRAPHIC AND SOCIOECONOMIC CHARACTERISTICS

	Treatment Group Patients	Control Group Patients
Age (Percent)		
Younger than 65	1.4	1.5
65 to 74	37.3	37.6
75 to 84	43.7	44.2
85 or older	17.7	16.6
Sex (Percent)		
Male	47.0	49.6
Female	53.0	50.4
Race (Percent)[a]		
White	92.8	94.4
Black	5.7	4.0
Other[b]	2.0	1.4
Hispanic, Latino, or Spanish Origin (Percent)	1.0	0.3
Educational Attainment (Percent)		
Less than high school	23.3	18.1
High school/GED	31.1	37.2
Some college	21.3	18.9
College degree (four-year)	24.4	25.8
Annual Income (Percent)		
Less than $10,000	14.5	11.4
$10,000 to $19,999	22.7	24.1
$20,000 to $29,999	20.4	22.4
$30,000 to $39,999	17.1	13.6
$40,000 to $49,999	10.3	9.0
$50,000 or more	15.0	19.6
Sample Sizes[c]	**735**	**728**

Source: Telephone survey of patients conducted by Mathematica Policy Research, Inc. 7 to 14 months after enrollment.

Note: Percentages for a given question may not sum to 100.0 due to rounding.

[a]Respondents could identify themselves as belonging to more than one race.

[b]"Other" includes American Indian or Alaskan Native, Asian, and Pacific Islander, and those of some other race or whose race was unknown.

[c]Sample sizes vary due to item nonresponse and include patients in six programs that started in April 2002 or earlier.

GED = General Educational Development.

The patients responding to our survey were fairly well educated and had widely varying income levels. Only about one-fifth reported having less than a high school education, compared with about 38 percent of beneficiaries nationally. That difference is consistent with the income levels reported—whereas just over a third of patients reported household incomes below $20,000, the proportion nationally among Medicare beneficiaries is 59 percent. Slightly more than one-third of the patients reported having incomes between $20,000 and $40,000, and one-fourth had incomes of more than $40,000.

D. PARTICIPATING PATIENTS AND ELIGIBLE NONPARTICIPATING BENEFICIARIES

In order to estimate the number of beneficiaries in an area who were eligible for the program during its first six months of operation and the proportion who actually enrolled in the demonstration, we simulated each program's eligibility criteria, using Medicare enrollment and claims data. We also compared characteristics of participants with characteristics of eligible nonparticipants to ascertain the extent to which participants were representative of each program's specified target population. Given the processing lag in Medicare claims, we were able to conduct this simulation only for the 11 programs that started enrolling patients by June 2002.

The simulation is subject to two limitations. First, we were unable to mimic all the programs' eligibility criteria with the information available from enrollment and claims data. Second, we were unable to restrict the pool of eligible beneficiaries to those in the hospitals and having the physicians from which the programs actually recruited patients. Thus, because we have overestimated the size of the eligible pool actually used by some programs, these comparisons must be interpreted with caution.

Our simulation shows that the programs' pools of eligible nonparticipants ranged in size from about 6,000 to more than 100,000 (Table II.7). Participation rates (the number of eligible participating patients, divided by the number of eligible nonparticipants plus the number of eligible participating patients; righthand column of the table) varied from fewer than one percent for 7 of the 11 programs to five percent for 1 program. These low rates do *not* imply that few people are interested in the programs, as many people probably were unaware of the program, others may have failed to meet additional eligibility criteria beyond those that can be simulated with claims data (such as a minimum severity of illness threshold), and others may eventually enroll during the remaining three and one-half years of the demonstration. The estimates simply give an indication of the number of Medicare beneficiaries living in program service areas and with program target conditions who were participating during the first six months of operation.

To test our simulation criteria, we applied the simulation to patients who actually enrolled in the programs. We found that, for each program, a number of patients did not satisfy the criteria. Overall, 85 percent of patients met the eligibility criteria that we applied to the claims data; however, the range who met the criteria extended from only 45 percent (for University of Maryland) to 96 percent (for Mercy). Patients failed to meet program eligibility criteria for a variety of reasons. For example, some programs relied on patients' or physicians' reports or on health care system medical or billing records to identify patients with target diagnoses, and to ascertain that those patients met the utilization criteria (such as a hospitalization during the past year); however, assessments of patients based on those reports or records might differ from assessments based on Medicare claims data. In addition, some programs' patients had addresses in the Medicare enrollment files that were not within the programs' specified service areas (for example, patients with post office boxes in other cities). Some programs were using additional inclusion criteria that were not based on diagnosis (for example, frailty). Criteria such as those

TABLE II.7

NUMBER OF PARTICIPANTS AND NONPARTICIPANTS

Program	Eligible Nonparticipants	Eligible Participants	Actual Participants	Participation Rate (Percent)
Avera	6,700	100	116	1.5
Carle	23,292	1,122	1,439	4.6
CenVaNet	38,751	702	784	1.8
Charlestown	55,265[a]	194	229	0.3
CorSolutions	13,221	101	171	0.8
Georgetown	6,726	29	43	0.4
Health Quality Partners	85,283	142	228	0.2
Jewish Home and Hospital	125,821	280	320	0.2
Medical Care Development	11,880	86	115	0.7
Mercy	11,332	291	322	2.6
University of Maryland	6,037	14	33	0.2

Source: Medicare Enrollment Database and National Claims History files covering 1999–2002. Data were not available for the four programs that started after June 2002 (Hospice of the Valley, QMed, Quality Oncology, and Washington University).

Note: "Eligible" nonparticipants and participants are beneficiaries whose reported Health Insurance Claim numbers are valid, who meet the Medicare coverage requirements of the Centers for Medicare & Medicaid Services during the reference month (month of intake for participants; third month after program startup for nonparticipants), and who fit our simulated eligibility criteria. This simulation was able to mimic only eligibility criteria reflected in Medicare enrollment and claims data (not, for example, reading level or severity of illness) and did not restrict the pool of eligibles to particular providers from which the programs recruited patients.

"Eligible participants" are also enrolled in the program during the first 6 months of enrollment.
The participation rate equals the number of eligible participants divided by the sum of eligible nonparticipants and eligible participants, multiplied by 100 to express as a percentage.

[a]The number of eligible nonparticipants for Charlestown includes all beneficiaries in the Baltimore areas who met the Charlestown diagnostic and service use criteria. The Charlestown program only recruited from among three Erickson Retirement Communities in the Baltimore area. Program staff estimated that 2,000 community residents are eligible for the demonstration program.

cannot be simulated with claims data. Finally, some programs enrolled patients who had a characteristic listed as an exclusion criterion in the program's protocol (for example, cancer or dementia). In addition, the programs and MPR differ slightly in the set of ICD-9 codes or counties used to define the eligible population. Given the fairly high proportions of patients in some programs who do not meet the eligibility criteria as simulated with Medicare data, our estimates of the numbers of eligible nonparticipants may be understated. However, any such underestimate is likely to be outweighed by the over-counting of the number of beneficiaries who had an opportunity to enroll, given the programs' limited recruiting efforts and referral sources during their first year of operations.

Comparisons of actual program patients with simulated eligible nonparticipants show some striking differences in characteristics (Table II.8). Almost all the programs enrolled a smaller percentage of very elderly beneficiaries (those age 85 or older) than were in the group of eligible nonparticipants. The exceptions were Charlestown and Jewish Home and Hospital. The Charlestown program recruited exclusively from Erickson Retirement Communities, but, because information on this type of residence is not recorded in Medicare claims, the eligible nonparticipants for that program include beneficiaries from the entire greater Baltimore area. The Erickson communities have high proportions of very elderly residents. Jewish Home and Hospital targeted frail beneficiaries, who generally are older than the general Medicare population.

Most programs enrolled relatively few beneficiaries who were dually eligible for Medicaid and Medicare, with the proportion of dually eligible participants in 4 of the 11 programs falling well below the rate of dually eligible nonparticipants. The rates of dually eligible beneficiaries among participants and nonparticipants were statistically similar in six of the programs. In only

TABLE II.8

COMPARISON OF PARTICIPANTS AND ELIGIBLE NONPARTICIPANTS

Program	Age at Intake (Percent) ≤65	65-84	≥85	Medicaid Buy-In[a] (Percent)	Hospital Discharge (Percent) Last Month	Last Year	Beneficiaries (Number)
Avera							
Participants	0.0	77.5	22.5	7.2	32.4	93.6	111
Nonparticipants	0.0	62.6	37.5	19.3	10.5	70	6,700
Carle							
Participants	0.8	86.6	12.6	3.5	2.5	26.9	1,381
Nonparticipants	7.9	75.5	16.6	13.6	5.1	36.2	23,292
CenVaNet							
Participants	0.0	87.1	12.8	6.9	4.7	48.6	764
Nonparticipants	0.0	85.8	14.2	10.1	3.3	26.0	38,751
Charlestown							
Participants	0.0	50.5	49.6	0.0	3.1	51.8	224
Nonparticipants	0.0	81.3	18.7	14.3	7.4	51.3	55,265
CorSolutions							
Participants	17.9	73.5	8.6	20.4	13.0	85.3	162
Nonparticipants	11.9	71.3	16.8	25.5	13.9	72.9	13,119
Georgetown							
Participants	0.0	83.4	16.7	14.3	26.2	95.4	42
Nonparticipants	0.0	76.5	23.5	13.1	11.8	76.5	6,726
Health Quality Partners							
Participants	0.0	90.9	9.1	2.7	2.7	18.6	221
Nonparticipants	0.0	87.5	12.6	5.5	2.1	16.5	85,283
Jewish Home and Hosptial							
Participants	0.3	65.5	34.2	38.8	6.5	39.4	307
Nonparticipants	0.0	80.3	19.7	24.2	4.2	28.0	125,821
Medical Care Development							
Participants	7.3	77.3	15.5	20.0	70.9	93.6	110
Nonparticipants	8.1	66.4	25.6	26.2	8.2	56.8	11,880
Mercy							
Participants	4.6	80.2	15.2	12.5	7.6	67.7	303
Nonparticipants	5.1	71.3	23.6	16.7	4.0	34.7	11,332
University of Maryland							
Participants	6.5	87.1	6.5	9.7	22.6	83.9	31
Nonparticipants	0.0	78.7	21.3	14.2	16.4	78.8	6,037

Source: Medicare Enrollment Database and National Claims History files covering 1999–2002. Data were not available for the four programs that started after June 2002 (Hospice of the Valley, QMed, Quality Oncology, and Washington University).

Note: The number of participants in this table (top row for each program) is lower than the number of actual participants shown in Table II.7. This table excludes participants whose reported Health Insurance Claim numbers are incorrect and participants who did not meet the insurance requirements of the Centers for Medicare & Medicaid Services during the month of intake.

Bold indicates that the difference between participants and eligible nonparticipants was significantly different from zero at the .05 level, two-tailed test.

[a] "Medicaid buy-in" refers to Medicaid payment of Medicare coinsurance and deductibles for dually eligible beneficiaries.

one program (Jewish Home and Hospital), were participants substantially more likely than eligible nonparticipants to be dually eligible.

For 7 of the 11 programs, participants were more likely than eligible nonparticipants to have had a hospitalization during the year preceding enrollment, suggesting that the programs were recruiting some of the sickest beneficiaries meeting their diagnostic criteria. By contrast, however, the participants in Carle were substantially less likely than eligible nonparticipants to have been hospitalized. Participants and eligible nonparticipants in the three remaining program had statistically similar rates of hospitalization during the year before enrollment.

Because hospitalizations account for the bulk of Medicare expenses, it is not surprising that Medicare reimbursement for participants during the year before enrollment was significantly greater than that for eligible nonparticipants in 7 of 11 programs (Table II.9). Average monthly Medicare reimbursement for participants ranged from roughly $500 for Carle and Health Quality Partners to roughly $2,500 for CorSolutions, Georgetown, and University of Maryland. Participants in the Carle program had significantly lower average monthly prior reimbursements than did their nonparticipating counterparts, probably because they were less likely to have been hospitalized.

To assess whether the programs were enrolling patients whose costs are comparable to costs in waiver application projections, we compared preenrollment Medicare spending for participants with waiver cost estimates. These comparisons may be misleading, however. Participant cost estimates for the year before intake were between 30 and 80 percent less than waiver cost estimates for 2003 for 5 of the 11 programs. (Participants in five of the other six had costs roughly equal to waiver estimates, and those in the sixth had costs that were greater.)

The following reasons may explain why some programs' waiver cost estimates were greater than their enrollees' preenrollment costs:

TABLE II.9

MEDICARE COSTS FOR PARTICIPANTS AND NONPARTICIPANTS
COMPARED WITH WAIVER ASSUMPTIONS

	Mean Monthly Medicare Reimbursement During One Year Before Intake (Dollars)						
	(1) Participants	(2) Nonparticipants	(3) P-Value	(4) Ratio of (1) to (2)	(5) Mean Monthly Medicare Reimbursement for Waiver Assumption	(6) Ratio of (1) to (5)	(7) Per Patient Per Month Program Payment[a] (Dollars)
Avera	1,497	1,161	**	1.30	1,479	1.01	316
Carle	477	625	***	0.76	742	0.64	159
CenVaNet	1,120	507	***	2.21	1,247	0.90	145—month 1 80—months 2+
Charlestown	1,208	1,113		1.09	1,488	0.81	218[b]
CorSolutions	2,687	1,994	***	1.35	2,078	1.29	437—months 1-9 287—months 10+ 187 maintenance[c]
Georgetown	2,424	1,947		1.24	3,476	0.70	360—month 1 320—months 2+
Health Quality Partners	465	357	*	1.30	644	0.72	130—high risk 110—moderate risk 50—low risk
Jewish Home and Hospital	1,410	987	***	1.43	1,581	0.89	379—high risk 259—moderate risk 74—low risk
Medical Care Development	1,454	1,193		1.22	2,390	0.61	297
Mercy	1,249	610	***	2.05	1,282	0.97	257
University of Maryland	2,731	1,958	*	1.39	2,979	0.92	350

Source: Medicare Enrollment Database and National Claims History files covering 1999–2002 for mean monthly Medicare reimbursement calculated over the year prior to enrollment. (For nonparticipants, we used July 15, 2002, as the pseudo-enrollment date in the programs that started in April, and we used September 15, 2002, for programs that started in June.) See Brown et al. (2001) for waiver assumptions for Medicare costs for the programs in the Medicare Coordinated Care Demonstration. Data were not available for the four programs that started after June 2002 (Hospice of the Valley, QMed, Quality Oncology, and Washington University).

[a]Payment rates in effect April 2002 through March 2003, rounded to the nearest dollar. Some programs classify patients by whether they are at high, medium, or low risk of incurring high medical costs.

[b]Charlestown also can bill $26 per month for physician oversight of care coordination.

[c]CorSolutions also can bill $366 per month for up to 60 patients to cover prescription medications.

*Difference between treatment and control groups significantly different from zero at the .10 level, two-tailed test.
**Difference between treatment and control groups significantly different from zero at the .05 level, two-tailed test.
***Difference between treatment and control groups significantly different from zero at the .01 level, two-tailed test.

- Waiver cost estimates include costs for those who die during the year; retrospective costs for those who enrolled do not. Costs for those who die in a year are four to seven times greater than for those who do not, making waiver costs higher than participants' preenrollment costs.

- Some programs had planned to enroll beneficiaries immediately after hospital discharge, so waiver cost estimates were calculated under that assumption. In practice, programs were unable to rapidly identify and enroll recently discharged patients. The costs for recently discharged patients are substantially higher than for those discharged at any time in the previous year, making waiver cost estimates higher.

- One program's eligibility criteria included characteristics found to be predictive of high future costs that could not be simulated with claims data. To approximate this target population, the waiver cost calculations were based on the one-third of area beneficiaries with the highest *actual* costs. Predictive models are not able to identify the cases with highest actual cost that reliably, so the program's enrollees' preenrollment costs were somewhat lower than the waiver estimates.

- The ICD-9 codes used to identify the target population in the waiver cost estimates and those used by the programs differed somewhat.

- The mix of beneficiaries in a program's target population defined for the waiver cost estimates may not reflect the mix of beneficiaries actually enrolled, due to referral practices and sources. For example, a program may draw enrollees only from particular hospitals.

- Sicker patients may be less likely than healthier ones to enroll. A number of programs reported that some patients, at the time they were approached, felt they did not have the energy to deal with another health care provider (despite the programs' efforts to convince these patients that care coordination could be most beneficial precisely during those times). Thus, waiver cost estimates would be higher than participant costs.

Four programs enrolled patients whose preenrollment costs were 25 percent or more below the waiver cost estimates, and two of these (Carle and Health Quality Partners) may have to generate more than the projected 20 percent savings in nondemonstration Medicare costs in order to cover the costs of their interventions. Programs had no incentive to avoid high-cost cases, as they were not at risk for their Medicare costs and may actually have had greater success in

reducing the need for expensive services among patients most likely to need them.[8] We saw no evidence that programs were targeting and enrolling patients who did not meet their eligibility criteria in order to increase their program size. The enrollment of some patients who do not meet the eligibility criteria appears to be due more to the programs' use of self-reports of prior service use to assess the eligibility of some potential enrollees.

We will return to comparisons of actual costs with the waiver cost estimates in the second synthesis report, when sample sizes are larger and follow-up claims data are available. In that report, we will assess whether any programs achieve 20 percent savings in nondemonstration Medicare costs relative to the control group, but with the savings failing to cover the cost of the intervention because the enrolled population has lower costs than were projected in the waiver application. If sample sizes permit, we also will assess whether savings on the subset of enrollees who *do* meet the claims-based eligibility requirements are sufficient to cover the cost of the intervention.

[8]As noted in the comparison of participants and eligible nonparticipants, participants in one program (Carle) had significantly lower average Medicare costs in the year preceding enrollment than did eligible nonparticipants. The cost differences arise in large part because a sizable proportion of enrollees did not meet the eligibility or utilization criteria *that are assessable with the claims data*, and those who do not meet them had much lower average costs. Carle enrolled some patients on the basis of physician reports that they had a particular condition and patient self-reports that they met the utilization criteria. Some of these patients did not meet the program's utilization criterion according to the claims data. The participants in Health Quality Partners actually had higher costs than did the program's nonparticipants. If its postenrollment costs exceed preenrollment costs, as expected, Health Quality Partners may not have difficulty covering program payments, assuming it reduces Medicare Part A and B expenditures by 20 percent.

III. WHAT DID THE PROGRAMS DO?

The host organizations participating in the Medicare Coordinated Care Demonstration (MCCD) were *not* charged with implementing a single model of care coordination; rather; they were free to design models based on their own experiences in delivering care coordination. Each had the goal of improving patient health and reducing health care costs, but different organizations targeted patients with different diagnoses and took different approaches to meeting that goal. In this chapter, we turn our attention to the six programs that began enrolling beneficiaries by the end of April 2002 (which we refer to as the "early programs"). We begin by providing a very brief sketch of each program that includes data on the frequency and mode of care coordinator contacts during the six months following the start of program operation. We then compare the programs along dimensions that the literature suggests are important to successful care coordination. The programs generally implemented their interventions as originally designed, making only relatively minor adjustments after they had begun operating.

A. SKETCHES OF THE EARLY PROGRAMS

The Carle and Charlestown programs are unique among the six early programs because they exist in environments in which "usual care" for elderly patients already includes a degree of collaboration between physicians and nurses. In addition, Carle's host is a large, rural, integrated delivery system that provides a number of structural supports for the program (such as ties to community-based support services and a sophisticated patient database). Charlestown's host is a retirement community with on-site geriatricians and extensive support services.

The CenVaNet and Health Quality Partners program hosts are providers of services that include disease management and care coordination. Each of these programs has had to market itself to area physicians, who, in turn, refer patients to the programs. However, CenVaNet is

owned partly by a group of 350 physicians, and it is those physicians whom the program has approached. Although the Health Quality Partners program's link to area physicians is more tenuous than CenVaNet's, many physicians became familiar with program staff through the organization's former affiliation with PennCare, a managed care contractor.

Medical Care Development and Mercy are hospital-based programs. The Mercy demonstration grew out of an outpatient-hospital case management program. Medical Care Development is a nonprofit health care research and service organization with longstanding roots in Maine. It oversees generally similar care coordination programs based in 17 hospitals across the state, all of which use the same case management software, but that can tailor their programs to their own visions and local resources.

The programs' approaches to patient recruitment differed, as did their enrollment targets and success in meeting those targets during the first year of operation. These factors, in turn, affected the programs' hiring of care coordinators, caseload size, and the nature of the care coordinators' contacts with patients. All of the care coordinators for the six programs were registered nurses, many had bachelor's degrees, and some had more advanced training. They also had substantial experience as community nurses or case managers or specialized in the programs' target conditions (for example, cardiac nursing). The six programs generally increased the number of care coordinators as enrollment and, thus, program revenue increased. By the end of the six-month period following the start of program operations, the programs had hired between 4 and 17 care coordinators (Table III.1). During month 6, average caseloads consisted of 25 patients, but caseload sizes ranged from as many as 52 and 44 patients per coordinator for Carle and for CenVaNet, respectively, to as few as for 4 patients per coordinator for Medical Care Development and 11 for Mercy. Coordinators had contacted the majority of patients enrolled (91 percent) at least once during the six-month period, and patients had

received an average of five contacts. The typical patient had between one and two contacts during month 6.

TABLE III.1

CARE COORDINATOR CONTACTS
DURING THE FIRST SIX MONTHS OF OPERATIONS
(Unless Otherwise Noted)

	Carle	CenVaNet	Charlestown	Health Quality Partners	Medical Care Development	Mercy	Total
Average Caseload Size *in Month 6*	51.9	44.4	26.5	19.8	4.2	10.8	24.9
Patients with at Least One Contact (Percent)	94.8	80.7	91.8	100.0	87.9	89.3	90.5
Mean Contacts per Patient (Number)	5.4	4.1	7.3	7.7	5.7	4.6	5.3
Mean Contacts per Patient *in Month 6* (Number)	1.1	1.2	2.2	2.9	1.9	1.3	1.4
Contacts Initiated by Care Coordinators (Percent)	87.8	92.1	86.8	94.0	99.1	90.5	89.9
Contacts by Telephone (Percent)	76.1	76.7	67.5	63.6	50.9	17.3	67.3
Care Coordinators (Number)	17.0	10.0	4.0	5.0	14.0	14.0	64.0
Patients (Number)	**657**	**374**	**110**	**104**	**58**	**159**	**1,462**

Source: Data covering each program's first six months of operation.

Notes: The number of care coordinators includes any staff who had contact with patients.

The Total column shows the average across the 1,462 patients enrolled for the top six rows and the total across the six programs for the bottom two rows.

Almost all contacts (90 percent) were initiated by care coordinators, as would be expected during early operations, when much activity revolved around assessment, and care coordinators were beginning to build relationships with patients. Most contacts were by telephone, although about one-third were conducted in person, in either the patient's home or the physician's office. Mercy's care coordinators made more than 80 percent of their contacts in person during the six months. The program's staff explained that face-to-face contact was key to developing trusting relationships between the coordinators and their rural patients. Half of Medical Care Development's contacts were in person, primarily because care coordinators also saw patients during cardiac rehabilitation and monitored exercise sessions.

B. ASSESSMENT, CARE PLANNING, AND MONITORING

Care coordinators for each of the early programs took a structured approach to the core care coordination tasks of patient assessment, care planning, and monitoring. However, they differed in the details of their approach.

1. Assessment

The assessment tools used by the six programs describe patients on a number of dimensions related to the patients' care coordination needs: physical, emotional, and psychological health; functional status; current health and health history; self-management knowledge and behaviors; current treatment recommendations, including prescribed medications; and need for support services (Table III.2). The assessment tools that CenVaNet and Health Quality Partners used also describe two patient attributes that can make it easier for care coordinators to help patients to improve adherence: readiness to change health behaviors and barriers to adhering to treatment recommendations.

TABLE III.2

ASSESSMENT, CARE PLANNING, AND MONITORING

	Assessment		Care Planning	Monitoring		
Program	Assessment Tools	Percentage with Assessment Contact Within Two Weeks[b]	Participants (in Addition to Care Coordinator)	Primary Mode	Minimum Frequency	Uses Technology
Carle	Omaha System Problem Classification Scheme (includes 44 types of problems in 4 domains: physiological, psychosocial, environmental, health maintenance) customized for demonstration program (for example, with questions about the receipt of disease-specific preventive care)	48	Physicians, community providers, patient, and caregiver/family	Telephone	Monthly	No
CenVaNet	PraPlus before random assignment to screen for eligibility Tool developed by program includes health, functioning, psychosocial, safety and informal supports, service needs, and education needs	23	Patient, caregiver/family Physician receives copy of care plan, but not expected to provide input or comments.	Telephone	Highest acuity—weekly Moderate acuity—biweekly Low acuity—monthly	Health Buddy for 74 patients with CHF or diabetes[c]
Charlestown	SF-12, PraPlus, Barthel Index (measures functioning) combined with tool developed for the program describing health, health behaviors/self-management, medications, and home safety	44	Other Charlestown departments serving patient (such as residential social services, home health) Reviewed with patient Physician must sign off on care plan	Telephone	Unstable and receiving home health or therapy—weekly Unstable but not using these services—biweekly Stable—monthly	No
Health Quality Partners	Before random assignment, to determine risk level: Sutter Health Questionnaire. For patients with few needs according to Sutter, PennCare basic disease-specific assessment After assignment to treatment group: PennCare comprehensive geriatric assessment for high-risk patients; PennCare comprehensive disease-specific assessment for moderate-risk patients; and no additional assessment for low-risk patients[a]	72	Patient, caregiver/family (for high-risk patients) Patient (for moderate-risk patients) No care plan for low-risk patients; focus is on knowledge deficits Physician receives copy of care plan, but not expected to provide input or comments.	Telephone	Monthly	No

TABLE III.2 *(continued)*

	Assessment		Care Planning	Monitoring		
Program	Assessment Tools	Percentage with Assessment Contact Within Two Weeks[b]	Participants (in Addition to Care Coordinator)	Primary Mode	Minimum Frequency	Uses Technology
Medical Care Development	Pfizer Health Solutions' CMS® software assessment: heart failure symptoms and knowledge, functional status, Fagerstrom index (measures nicotine dependence), medication compliance, and diet knowledge	36	Software generates draft care plan based on assessment Primary care physician and office staff, hospital floor nurse, patient, family/partner	Telephone	Weekly for first four weeks, then monthly as specified by CMS® software protocol	No
Mercy	Similar to Mercy home care assessment, including functioning, nutrition, medications, mental status, prognosis for goal achievement, unmet need for services, emergency plan, and physical assessment	72	Social worker, chaplain, nutritionist, patient Physician must sign off on care plan annually	In person during first year, with goal of increased telephone contact in future	Monthly	Tel-Assurance Patient Support Program for two CHF patients[d]

Source: Program contacts; assessment timing from program data covering first six months of program operations.

Note: The PraPlus identifies older individuals who are at high risk for using health services heavily in the future. The SF-12 measures physical and mental health. The Barthel Index measures functional status. The Sutter Health Questionnaire is a 17-item tool to predict risk of common adverse outcomes (for example, hospitalization, emergency room use, and falls) for medically complex and frail individuals.

[a]PennCare, a managed care risk contractor, was the owner of Health Quality Partners until July 2001.

[b]The proportion of treatment group patients enrolled during the first six months of operations who had at least one contact for assessment within two weeks of enrollment.

[c]CenVaNet was using the Health Buddy for 74 patients as of February 2003. This device records patients' responses to a series of questions about health and symptoms and transmits them to program care coordinators each day. Patients had the devices for just six months.

[d]Mercy was using the Tel-Assurance Patient Support Program for two patients with CHF as of April 2003. Tel-Assurance is a home monitoring device that telephonically transmits patients' answers to CHF-related questions on a daily basis.

CHF = congestive heart failure; CMS® = Clinical Management System; SF-12 = SF-12® Health Survey; PraPlus = PraPlus™ Screening Instrument.

Three programs used existing tools, as well as tools that they had developed specifically for or had adapted to the program. Charlestown used the SF-12® Health Survey (SF-12), PraPlus™ Screening Instrument (PraPlus), and Barthel Index, along with an assessment tool that it developed to describe health, health behaviors, health self-management, medication use, and home safety. CenVaNet administered the PraPlus before random assignment to screen applicants for eligibility. After random assignment, it administered a tool that it developed under a managed care contract; the tool describes health, functioning, psychosocial problems, service needs, and education needs. Before random assignment, in order to screen for eligibility and assign patients a program risk level, Health Quality Partners administered the Sutter Health Questionnaire (Sutter) and, for patients who had relatively fewer needs according to the Sutter, administered a basic disease-specific assessment developed by its former parent company, PennCare. Patients who had relatively greater needs according to either the Sutter or the basic assessment were assessed again after random assignment. For that assessment, the program used other tools developed by PennCare.

Carle and Medical Care Development relied primarily on published or preexisting assessment tools. Carle customized the Omaha System Problem Classification Scheme, a standardized community nursing tool developed by researchers funded by the National Institutes of Health. Medical Care Development used Pfizer Health Solutions' Clinical Management System (CMS®) software to conduct assessment, care planning, and monitoring activities.

Mercy developed assessment tools specifically for the program based on the hospital's home care assessment instrument. The content is similar to that of the OASIS home health assessment but also includes the program's own assessment of spiritual well-being.

Care coordinators for the six programs primarily assessed patients in person (not shown). Care coordinators from several programs stated that they preferred to conduct these assessments

in their patients' homes to get a sense of how that environment affected the patients' health and behavior. Health Quality Partners assessed its moderate-risk patients in its program office or in the offices of the patients' physicians but assessed high-risk patients in their homes. Carle and Medical Care Development conducted some assessments in their patients' homes and others in clinics or the hospital, depending on the patients' preferences.

Because care coordination cannot proceed without a patient assessment, failure to complete the assessment soon after enrollment would have limited a program's opportunity to improve patient outcomes in the short run. During the first six months of operations, the programs varied considerably in the percentage of enrolled patients who had had at least one contact for assessment within the two weeks after random assignment to the treatment group, from 23 percent for CenVaNet and 36 percent for Medical Care Development to 72 percent for Health Quality Partners and Mercy. Although Medical Care Development's care coordinators did not assess a majority of that program's enrolled most patients within two weeks of enrollment, they did contact most (78 percent) of the patients within that period (not shown). Medical Care Development's care coordinators used the initial contacts to discuss the details of the program, and to schedule an appointment to begin the assessment. (By contrast, only 25 percent of CenVaNet's patients were contacted by care coordinators within two weeks. However, at the end of six months, the program's care coordinators had average caseloads 10 times the size of the average caseloads of Medical Care Development's care coordinators and therefore may not have had time to contact many patients during that two-week period.)

Making care coordinators responsible for patient outreach or enrollment activities (as was the case in five of the six early programs) reduced the amount of time that these staff could devote to patient care, especially during the first six months, when programs focused on enrollment. CenVaNet's staff noted that, despite its having hired two part-time staff to call

beneficiaries who had received letters inviting them to participate, their program had a particular problem with this situation. Although the part-time staff set up appointments for the care coordinators, the care coordinators still had to visit patients in their homes to complete the enrollment process. Medical Care Development also reported that its care coordinators had difficulty balancing the competing program demands of patient recruitment and patient care. Moreover, the program's coordinators had to continue to fulfill nonprogram nursing responsibilities for the hospitals that housed the program, further reducing their availability for program activities.

2. Care Planning

After an assessment has identified patient needs and coordination gaps, care coordinators develop care plans to fill the gaps, set goals for patients, and, in some cases, set goals for the patients' providers. Care coordinators for all six programs worked with their patients to develop care plans. Mercy's care planning included a consultation with a nutritionist. (Health Quality Partners does not develop care plans for its low-risk patients, who constitute about 10 percent of participants; instead, the program focuses on reducing the self-management deficits of that group by sending the patients to disease-specific self-management classes.)

Although most of the programs used paper or electronic care plan templates to guide their care planning efforts, the CMS® software that Medical Care Development used and the InformaCare® software that CenVaNet used automatically drafted care plans based on assessment data. Medical Care Development's care coordinators then tailored the draft plan for each patient, using input from the patient, the patient's physician, and the nurses who provided care during the hospitalization that identified the patient for the program. CenVaNet's care coordinators tailored the draft plan by relying primarily on input from the patient and the patient's family.

Care coordinators for all six programs used the completed care plans to schedule their contacts with patients for the subsequent few weeks or months. They also shared completed care plans with the patients' primary care physicians as a way of keeping the physicians informed about program plans for their patients, as discussed in Section E.2.

3. Monitoring

Regular patient monitoring is the foundation of ongoing care coordination activities. It gives care coordinators opportunities to teach patients self-management; assess their patients' progress; find out about changes in patient health, functioning, or social support that might suggest the need for medical intervention, or that might affect treatment adherence; and find out about adverse events, such as emergency room visits, or about inconsistent advice given by different providers. Five of the early programs monitored patients primarily by telephone, although all six occasionally saw patients in person either in the patients' homes or in the offices of the patients' physicians. During its first year of operation, Mercy's care coordinators saw patients primarily in person; in its second year, however, the program plans to replace some in-person visits with telephone contacts.

All six programs intended to monitor all patients at least monthly. CenVaNet and Charlestown classified patients according to acuity levels to indicate whether patients might require more frequent followup at specified intervals. Health Quality Partners classified patients in this way as well, although the frequency of contact for patients at higher acuity levels was left to the judgment of the care coordinators. Medical Care Development followed up with patients more frequently during the first few weeks or months after enrollment and then reduced the frequency of contact over time. In all six programs, however, the care coordinators were given discretion to contact patients more frequently, if necessary.

Program data classified care coordinator contacts for monitoring purposes as routine monitoring, as followup on abnormal test results, or as followup on expected medical or support services (such as home care or transportation). The data also tracked coordinator contacts intended to provide emotional support. Care coordinators provided routine monitoring to roughly two-thirds of patients enrolled during the first six months (Table III.3). Nineteen percent of patients had contacts to monitor abnormal test results, 15 percent had contacts to monitor the receipt of medical or support services, and slightly more than one-third had contacts during which care coordinators provided emotional support. Charlestown and Mercy had the greatest proportions of patients who were contacted for monitoring. CenVaNet and Medical Care Development had among the smallest proportions, consistent with their delays in conducting patient assessments. (However, half of Medical Care Development's patients had contacts for emotional support.)

TABLE III. 3

PATIENT MONITORING CONTACTS DURING THE FIRST SIX MONTHS OF OPERATIONS

Percentage of Patients with Contacts for:	Carle	CenVaNet	Charlestown	Health Quality Partners	Medical Care Development	Mercy	Total
Routine Monitoring	65.4	55.3	84.5	84.6	37.9	88.7	67.1
Monitoring of Abnormal Results	17.4	10.4	15.5	37.5	13.8	40.9	19.3
Monitoring of Services	14.8	9.1	35.5	16.3	12.1	11.9	14.6
Provision of Emotional Support	32.7	8.3	71.8	36.5	50.0	84.9	36.0
Patients (Number)	**657**	**374**	**110**	**104**	**58**	**159**	**1,462**

Source: Data covering each program's first six months of operation.

Note: The Total column shows the average across the 1,462 patients enrolled during the first six months of operations for the first four rows and the total across the six programs for the last row.

Only two of the early programs used automated devices to monitor patients, and they did so only as pilot tests with limited sets of patients. As of early 2003, 74 CenVaNet patients with congestive heart failure (CHF) or diabetes (about 15 percent of the roughly 500 patients enrolled at that time) were using the Health Buddy, a device that records and transmits patients' responses to questions about health and symptoms. Patients were to have use of the Health Buddy for only a six-month trial period. Also as of early 2003, two of Mercy's CHF patients were using a Tel-Assurance Support Program, which transmits patients' answers to CHF-related questions to the program each day. (Future reports will describe the more extensive use of monitoring devices by later-starting programs.)

C. DATA SYSTEMS AND REPORTING

Monitoring program activities and progress toward program goals is greatly facilitated by a comprehensive, flexible data system that can generate a variety of reports. Each of the six early programs developed primary databases, and some developed or had access to other databases. The programs generated a variety of reports from these databases.

1. Types of Data Systems

All six programs had an electronic data system or, in some cases, several systems, to help them to plan and monitor program activities (Table III.4). The programs had varying degrees of access to other databases describing patients' use of other health services that might affect coordination efforts. Three programs used commercially available, Web-based case management software. Both CenVaNet and Medical Care Development used products developed by Pfizer Health Solutions (InformaCare® and CMS®, respectively); Charlestown used the Canopy® system. CenVaNet also sent data to InformaCare from the Microsoft Access database it used to collect evaluation and enrollment data. Charlestown's care coordinators had

TABLE III.4

DATA SYSTEMS AND REPORTING

Program	Primary Data Systems for Program	Other Systems Accessed	Reports Generated: Applications/ Enrollment	Reports Generated: Program Process/ Reminders	Reports Generated: Patient Behavior[a]	Reports Generated: Clinical Indicators/ Outcomes
Carle	Care Management Information System	Links to Carle electronic medical records system (EpicWeb) Staff also can enter physician appointment scheduling program	Yes	Yes	Yes	Indicators: yes Outcomes: planned
CenVaNet	InformaCare (Pfizer Health Solutions) Access database for evaluation and enrollment	Can send data from Access to InformaCare	Yes	Yes	No	Indicators: planned Outcomes: planned
Charlestown	Canopy CM (Canopy Systems)	Staff also can enter physician appointment scheduling program	Yes	Yes	No	Indicators: planned Outcomes: yes
Health Quality Partners	Access database	None	Yes	Yes	No	Indicators: planned Outcomes: planned
Medical Care Development	Clinical Management Systems (Pfizer Health Solutions)	None	No	Yes	Yes	Indicators: yes Outcomes: yes
Mercy	Case Management Information System	Staff generate service use and cost reports from hospitals' patient databases	Yes	No	Yes	Indicators: yes Outcomes: yes

Source: Program contacts.

[a]Includes adhering to diet, medication, and exercise recommendations; monitoring indicators, such as weight gain and blood sugar level; and use of nonmedical treatments, such as postural drainage.

access to its host organization's physician scheduling program, which enabled the program to check on appointments that patients had made, and to determine whether the patients kept them or had multiple appointments that required follow-up monitoring by the care coordinators.

The Carle and Mercy programs used databases developed by their host organizations and adapted for the demonstration. Similarly, Health Quality Partners adapted a database developed by its former parent, PennCare. Carle's care coordinators were able to transfer data between the program's database and the Carle system's electronic medical record database, which contains clinical notes and test results. The care coordinators also were able to access Carle's physician scheduling program, where they could view patterns of patients' previous appointments *and* quickly make appointments for patients, if necessary. In addition, the care coordinators received email alerts whenever one of their patients had an encounter in the Carle system. Mercy's database was a stand-alone tool, but the program generated reports on patient service use and costs from its participating hospitals' data systems. During Health Quality Partners' first year, its Access database included information related primarily to enrollment, care coordinators' activities, and care coordinators' productivity. The program relied heavily on paper records of patient assessments, care planning, and monitoring. (In its second year, it plans to add patients' clinical indicators to its Access database based on review of physicians' medical records.)

2. Reporting

Ideally, program administrators would use reports generated by their data systems to ensure that the intervention is being delivered as intended, and to improve care, if necessary. Reports also may be viewed as both a starting point for discussions about program activities and tools for problem solving. As one program director noted, without a comprehensive set of monitoring reports, "You're just praying that you're providing the intervention."

Five of the six early programs used their data systems to generate enrollment reports; the exception was Medical Care Development, which left the oversight of enrollment to each of its participating hospitals (Table III.4). It was crucial during the first year of operation—a period during which enrollment activity was heaviest and, for a number of programs, fraught with difficulties—that program administrators were aware of the numbers of beneficiaries their staffs were contacting about enrolling, the numbers who actually enrolled, and the providers identifying these enrollees. In addition, knowing how many beneficiaries had target diagnoses but did not meet more specific eligibility criteria helped some programs to revise their criteria. For example, Charlestown added a diagnosis (chronic obstructive pulmonary disease) to its eligibility criteria after reports showed that the program was not obtaining the expected level of enrollment from its original criteria.

Five programs used their data systems to generate reminders for care coordinators in the form of prioritized daily task lists (Health Quality Partners), or reports about the interval since patients had last been contacted (Carle). Medical Care Development's CMS® provided care coordinators with a schedule for contacting each patient and a list of questions to ask at each contact.

During the first year of operations, only three programs were generating reports that would enable care coordinators to track changes in patient adherence to treatment recommendations (for example, taking medications as prescribed or following a low-salt diet), in changes self-monitoring (for example, daily weighing or blood sugar testing), or changes in self-care (such as use of postural drainage by those with chronic lung disease).

Finally, four programs used their databases to generate reports on patients' clinical indicators and outcomes (for example, hospitalizations), and two planned to do so during their second year of operations.

D. PROGRAMS' EXPECTATIONS OF PHYSICIANS

Although each program recognized the importance of physicians' support to improving patient health, most also realized that physicians would have little, if any, time to become actively involved with the program. Consequently, only 1 of the 6 early programs (and, indeed, only 5 of the 15 participating programs) required a relatively high level of engagement from their physicians; these programs had adopted the goal of improving physicians' clinical practice as a fundamental approach to improving patient health. The other programs made only very modest requests of their physicians, and they expended substantial efforts to tailoring their communications with physicians to suit the physicians' preferences in terms of frequency and mode of contact.

1. How Physicians Learned About the Programs

Different programs used different methods to market the demonstration to local physicians during the months leading up to its start. Some programs developed physician advisory boards or cultivated local physician opinion leaders to publicize the program, and to elicit physicians' acceptance and support. Others recruited physicians and physician groups as primary sources of patient identification by first making presentations at professional and staff meetings to explain program goals and procedures. Still others introduced physicians to the program only after they had identified one of the physicians' patients as eligible for it.

2. The Physicians' Role in Recruiting Patients

Most of the programs, including all six early programs, asked physicians to review patients for program appropriateness. In some programs, the physician review took place after the program had identified patients by searching an electronic health system database; in other programs, it was part of the process of having physicians refer their own patients (Table III.5).

TABLE III.5

PROGRAMS' EXPECTATIONS OF PHYSICIANS

Program	Review Patients for Program Appropriateness	Refer Patients Directly to Program	Participate in Care Planning[a]	Respond to Care Coordinator Requests	Call Care Coordinators with New Information	Provide Standing Orders to Care Coordinators	Are Paid for Program Participation
Carle	Yes	Desired	Provides input	Yes	Yes	Yes	Yes (for attending meetings)
CenVaNet	Yes	Desired	Receives copy of plan	Yes	No	No	No
Charlestown	Yes	Desired	Must review	Yes	No	No	Yes (per patient month)
Health Quality Partners	Yes	Desired	Receives copy of plan	Yes	No	No	No
Medical Care Development	Yes	No	Provides input	Yes	No	No	Yes (per patient month)
Mercy	Yes	Desired	Must review	Yes	No	No	No

Source: Program contacts.

[a]"Provides input" means that care coordinators elicit physicians' input while drafting care plans; "Must review" means that the program requires the physician to review the final care plan.

With the exception of Medical Care Development, which targeted only hospitalized patients, all of the early programs welcomed direct physician referrals but did not expect to receive many during the first year of operations. Staff of these programs stated that it was difficult for physicians to bear the program in mind, and to subsequently find time to discuss it with patients during office visits. Some programs believed that direct physician referrals would increase over time, as physicians began to recognize the program's value for their patients.

3. The Physicians' Role in Care Planning

Four of the six early programs expected physicians to take an active role in care planning. Care coordinators for Carle and Medical Care Development asked physicians for input while developing patient care plans. Charlestown's and Mercy's physicians have been charged with reviewing and approving care plans; Mercy physicians do so annually. CenVaNet and Health Quality Partners provided physicians with copies of care plans, but these programs *have not required* either input or review from the physicians.

4. The Physicians' Interaction with Care Coordinators

All the early programs (and, indeed, all 15 programs) operated under the assumption that physicians would respond in a timely way to any care coordinator's request to discuss the care of a specific patient (for example, a patient whose symptoms suggested that a change in medication was necessary). Most programs elicited and followed their physicians' preferences on methods of communicating less urgent information. Some physicians expressed a preference for annual or semiannual written reports; others preferred to receive less formal email updates.

Although all six programs expected care coordinators to initiate contact with physicians, only Carle expected that physicians would routinely initiate with contact care coordinators, such as to communicate about a change in the condition of a specific patient that would affect care

coordination. (After a year of operation, Carle's physicians were calling care coordinators for such reasons as to follow up on issues that had arisen during office visits, to be briefed before visits, and to check whether patients were taking all the medications recorded in their charts.) Staff from some of the other programs believed that most physicians had difficulty remembering which of their patients were receiving care coordination, especially during the first year.

Carle also was the only early program that *required* physicians to give care coordinators standing orders to schedule tests, order medications, and provide advice to patients about behavior modification. Several factors contributed to Carle's ability to obtain its physicians' agreement on this issue, which must be renewed each year. First, collaboration between physicians and nurses is the status quo in the Carle system. Second, the program's physician advisory group included physician leaders from all Carle departments and clinics affected by the demonstration program, and this group exerted its influence over the physicians. Finally, most of Carle's physicians knew the program leadership, all of whom had long tenures with Carle.

Mercy *requests* that physicians provide care coordinators with standing orders and staff report that roughly half the physicians they are working with provide them. Orders pertain primarily to titrating medications for heart failure patients.

5. Physician Payment

Another factor contributing to Carle's high expectations for physician involvement was that the program reimbursed physicians for attending formal meetings with care coordinators and with care coordinators and patients (as well as for reviewing practice guidelines). Charlestown and Medical Care Development provided physicians with a monthly payment for each of their patients in the care coordination program. The three other programs did not pay physicians for the time spent interacting with care coordinators.

E. IMPROVING COMMUNICATION AND COORDINATION

Improving communication across providers, improving communication between providers and patients, and coordinating patient care are fundamental to improving the health care and health of individuals with chronic conditions. All of the early programs worked actively during their first year of operations to achieve these improvements.

1. Approach

Five of the six early programs chose to improve communication and coordination primarily by teaching patients about the types of self-care and medical care necessary to manage their conditions, and by providing them with the skills to better communicate with physicians (Table III.6). These programs educated patients about the nature and day-to-day management of their medical conditions. The program also taught patients how to communicate more effectively with their physicians. As part of that effort, the programs helped the patients to develop lists of questions to be brought to physician appointments, and they taught the patients to recognize when it was necessary to ask primary physicians to intervene with specialty physicians (for example, to resolve conflicting advice or problems resulting from medication interactions). Because the care coordinators of the sixth program (Charlestown) had worked closely with the program's physicians before the demonstration began, they adopted the approach of intervening directly with physicians on behalf of patients when problems of communication or coordination arose.

2. Opportunities for Communication

Even in programs that sought to teach patients to better communicate with their physicians, care coordinators occasionally had to communicate directly with physicians. The care

TABLE III.6

IMPROVING COMMUNICATION AND COORDINATION

Program	Goal	Primary Approach	Patient Specific Formal Communication	Co-Location and Caseload Allocation	Care Coordinator Role in Ensuring Guideline Adherence	Process for Learning About Adverse Events[a]
Carle	Yes	Teach patients	Semiannual meetings between care coordinators and physicians Periodic conferences among care coordinators, physicians, and patients	Care coordinators located in same clinics as physicians Physician has same care coordinator for all his or her patients	Will inform physician when treatment is not consistent with guidelines	Carle system e-mail alerts, patient self-reports
CenVaNet	Yes	Teach patients	Annual written patient reports to physicians	No co-location Physician has same care coordinator for all his or her patients	None	Patient self-reports
Charlestown	Yes	Direct care coordinator intervention	None	Care coordinators located in same community medical center as physicians Physician has same care coordinator for all his or her patients	None	Daily community incident and EMS reports, patient self-reports
Health Quality Partners	Yes	Teach patients	Each patient encounter generates a report that is mailed or faxed to the physician	Care coordinators see patients in physicians' offices if space is available Physician has same care coordinator for all his or her patients	Will inform physician on a patient-by-patient basis when treatment is not consistent with guidelines	Patient self-reports
Medical Care Development	Yes	Teach patients	Regular written reports at hospital-specific intervals	Care coordinators located in hospitals where physicians have admitting privileges Physician has same care coordinator for all his or her patients	Will inform physician on a patient-by-patient basis when treatment is not consistent with guidelines	Review of hospital admissions log Patient self-reports (infrequently)
Mercy	Yes	Teach patients	Physicians review and sign care plans once a year Care coordinators schedule quarterly meetings with physicians to discuss some patients	Care coordinators located in same clinics as physicians Physician has same care coordinator for all his or her patients	Will inform physician on a patient-by-patient basis when treatment is not consistent with guidelines Care coordinator can consult with pharmacist about medication concerns	Daily reports from hospital information system, patient self-reports

TABLE III.6 *(continued)*

Source: Program contacts.

Note: For brevity, this table refers to communication and coordination with physicians but includes all primary care providers, such as nurse practitioners and physicians' assistants.

[a]Adverse events include emergency room visits, hospitalizations, polypharmacy, and conflicting or inconsistent treatment recommendations from different providers.

coordinators' ability to communicate effectively was either enhanced or hampered by the program features associated with program–physician integration discussed Chapter II. Most of the programs established formal communication mechanisms (such as regularly scheduled meetings or written reports). Carle scheduled twice-yearly meetings between care coordinators and physicians to discuss patients' progress, as well as periodic meetings that patients also attended. Mercy's care coordinators could schedule formal meetings with physicians to discuss the care of particular patients. CenVaNet, Health Quality Partners, and Medical Care Development each sent physicians written patient reports at different intervals. Mercy had physicians review and approve patient care plans annually. By contrast, Charlestown's care coordinators neither held regular, formal meetings with physicians nor sent the physicians written patient reports.

Five early programs (one of which was Charlestown) provided opportunities for informal communications. Their care coordinators and physicians practiced in the same clinics or settings and therefore saw each other daily. CenVaNet was the only one of the six early programs to limit its care coordinators' contacts with physicians to formal communications. The program made this decision because the care coordinators practiced primarily out of the program office and would not normally see the physicians during the course of a work day.

All six early programs assigned care coordinators to patients such that most physicians had to deal with only a single program care coordinator for all of their patients. This structure probably made it simpler for physicians to respond to care coordinators' requests and facilitated the development a good working relationship.

3. Process for Coordinating Care

In addition to keeping lines of communication between physicians and patients open, care coordination entails such activities as ensuring that (1) patients receive the care recommended in

evidence-based, disease-specific guidelines, (2) issues of conflicting advice from physicians and of polypharmacy are identified and resolved, and (3) the cause or causes of adverse events are identified and a plan developed to prevent them from recurring.

Care coordinators for four of the early programs were expected to let physicians know when they thought patient treatment was not conforming to guidelines. (The coordinators also were expected to teach patients to do so themselves.) Most programs described the activity as one that required a high level of tact and diplomacy, and as one to be undertaken on a patient-by-patient basis. Care coordinators had various allies in this task, including program medical directors. Mercy's care coordinators could ask pharmacists to help to resolve questions about medication regimens. Carle's care coordinators could consult with clinic directors to confirm whether an apparent problem should be brought to the appropriate physician's attention. Relative to the care coordinators of the three other programs, Carle's care coordinators may have been more proactive in approaching physicians because Carle focused on improving physician practice by having care coordinators "hold doctors to task" about adherence to guidelines.

One challenge of fee-for-service medical care is the absence of a central data system to help to identify adverse events, such as emergency room visits or hospital admissions, in a timely way. Programs that were not hosted by health systems, like CenVaNet and Health Quality Partners, relied solely on patients' self-reports of these events; the others could scan hospital registration databases or admissions logs. Carle's care coordinators received email alerts from the Carle system whenever any of their patients had encounters with Carle's providers. Charlestown's care coordinators reviewed daily community incident and emergency services reports to track their patients' adverse events. All six programs relied on patients' self-reports to learn about problems of polypharmacy or conflicting advice (or, more specifically, relied on care coordinators to ask the appropriate questions to elicit such reports).

F. IMPROVING ADHERENCE THROUGH PATIENT EDUCATION

All six early programs sought to improve patient adherence to treatment recommendations. They sought to achieve that outcome through patient education.

1. Curricula and Materials

All six programs taught patients about the nature and course of their target conditions; signs and symptoms that might result from failure to adhere to treatment recommendations, or that might indicate the necessity of changing medication or other treatment; and recommended routine testing, self-care techniques, and tips for improving adherence and other health-related behaviors (Table III.7). Most programs covered comorbid conditions common among patients with their target diagnoses; for example, programs targeting heart conditions provided education about diabetes. The five programs that sought to teach patients to communicate more effectively with their physicians included it in their patient education as well. In addition, Carle, Health Quality Partners, and Medical Care Development taught patients how to locate and obtain community resources, such as home care or financial assistance to purchase prescription medications.

Five programs developed their own curricula, but all six programs used either materials developed in house (based on national guidelines) or a combination of in-house and published patient education materials. Charlestown's care coordinators downloaded teaching materials

TABLE III.7

IMPROVING ADHERENCE THROUGH PATIENT EDUCATION

	Curriculum and Materials			Education Providers		
Program	Topics	Who Developed	How Adapted to Patients	Who?	Type of Patient Education Training	How Is Education Effectiveness Assessed?
Carle	Etiology/disease process Signs and symptoms Self-care and health behaviors/how to change Communication with providers Community resources	Curriculum: developed by program Materials: published and in-house	If patient has cognitive impairment, involves caregiver Materials at eighth-grade level; non-English and picture versions available	Care coordinators Use of community-based diabetes and smoking cessation classes, and nutrition groups limited by rural environment	Part of program orientation; includes review of patient curriculum and materials Regular staff meeting discussion about education process and actual program experiences	Review of patient self-reports of adherence and data-system-generated reports on clinical indicators
CenVaNet	Etiology/disease process Signs and symptoms Self-care and health behaviors/how to change Communication with providers	Curriculum: Pathways, developed by program Materials: in-house	If patient has cognitive impairment, involves caregiver Materials written at various grade levels; patients assessed to determine necessary level	Care coordinators	No program-specific training	Review of patient self-reports of adherence and data-system-generated reports on clinical indicators Quiz patients on material presented
Charlestown	Etiology/disease process Signs and symptoms Self-care and health behaviors/how to change	Curriculum: developed by program Materials: published (MD Consult software) and in-house	If patient has cognitive impairment, simplifies teaching as necessary and involves caregiver	Care coordinators	No program-specific training, but all care coordinators are highly experienced patient educators	Review of patient self-reports of adherence and data-system-generated reports on hospital admissions and emergency room visits Care coordinators ask patients to repeat information back to them
Health Quality Partners	Etiology/disease process Signs and symptoms Self-care and health behaviors/how to change Communication with providers Community resources	Curriculum: developed by program Materials: published and in-house	Program assesses patient's readiness to learn and adapts education accordingly Uses visual aides	Care coordinators (for moderate-risk and high-risk patients) Group education provided by a local hospital (for diabetes) or by the program (for heart disease) (for low-risk patients)	Care coordinators role-play, and their supervisors discuss with them how to structure teaching	Care coordinators ask patients to repeat information back to them

TABLE III.7 *(continued)*

	Curriculum and Materials			Education Providers		
Program	Topics	Who Developed	How Adapted to Patients	Who?	Type of Patient Education Training	How Is Education Effectiveness Assessed?
Medical Care Develoment	Etiology/disease process Signs and symptoms Self-care and health behaviors/how to change Communication with providers Community resources	Curriculum: developed by each care coordinator Materials: published (from CMS® software) and hospital publications	If patient has cognitive impairment, involves caregiver Materials designed for low literacy level	Care coordinators Community-based educators	No program-specific training	Some care coordinators quiz patients on material presented
Mercy	Etiology/disease process Signs and symptoms Self-care and health behaviors/how to change Communication with providers	Curriculum: published Materials: published and in-house	Hospital's regional health education department helps adapt education to varying needs as they arise	Care coordinators Mercy's diabetic education classes	Part of program orientation but depends on experience and skill levels of care coordinators	Review of patient self-reports of adherence and symptom management

Source: Program contacts.

about a variety of health topics, using a software product. By contrast, Medical Care Development relied on each care coordinator to design her own patient education intervention, using materials found in the CMS® software or developed by the hospital in which she was based.

A one-size-fits-all approach to patient education is seldom effective, as patients differ in learning style, literacy level, and cognitive ability. Most of the programs were therefore prepared to adapt education interventions as necessary. For example, Health Quality Partners specifically assessed the readiness of individual patients to learn and adapted its educational intervention accordingly. Most care coordinators who worked with cognitively impaired patients would simplify their teaching messages or would include the caregivers of those patients during the education. Carle and Health Quality Partners developed alternative education materials that were based on pictures or props, rather than on text, for patients with low literacy levels. Carle also could provide teaching materials in languages other than English.

2. Educators and Their Training

Most program education was provided by care coordinators, almost all of whom were registered nurses. Even though basic nursing education covers patient teaching, three of the early programs provided additional patient teaching training to care coordinators as part of their program orientation and through ongoing discussion in staff meetings. The three other programs relied on the care coordinators' nursing education and practical experience to provide them with the necessary skills to teach patients.

Four programs supplemented the care coordinator patient education by sending patients to community-based education programs to learn more about specific diagnoses (for example, diabetes), or to learn behavior modification techniques (such as for smoking cessation or weight loss). Medical Care Development sent patients to stress management classes, sent patients with

heart failure to monitored exercise classes, and sent patients with coronary artery disease to cardiac rehabilitation. Group education was less common for patients living in rural areas, however.

3. Assessment of Education Effectiveness

All six programs adopted methods to assess how well patients were responding to the education intervention, a key component of effective teaching. Some programs (for example, CenVaNet and Medical Care Development) quizzed patients about what they had learned. All of the programs with the exception of Medical Care Development relied on patients to report to the care coordinators during routine monitoring conversations about what they had learned and about their adherence behaviors. Carle, CenVaNet, and Charlestown also analyzed patients' clinical indicators, such as blood glucose levels, and service use, such as emergency room visits, to determine whether patients were internalizing educational messages and improving their adherence to treatment recommendations.

4. Care Coordinator Contacts for Education

The majority of patients who had enrolled during the first six months of operations (81 percent) had at least one contact during which care coordinators provided education about a specific chronic condition or about appropriate self-management for a condition (Table III.8). Slightly more than half (56 percent) also had contacts during which care coordinators explained how and why to take a medication or discussed the possible side effects of medications. Slightly less than half (44 percent) had contacts during which care coordinators explained medical tests or procedures.

TABLE III.8

PATIENT EDUCATION CONTACTS DURING THE FIRST SIX MONTHS OF OPERATIONS

Percentage of Patients with Contacts for:	Carle	CenVaNet	Charlestown	Health Quality Partners	Medical Care Development	Mercy	Total
Education	81.4	77.0	80.0	96.2	70.7	83.0	81.0
Explanations About Medications	55.7	49.2	64.5	93.3	32.8	48.4	55.7
Explanations About Tests or Procedures	55.3	36.1	30.0	65.4	32.8	11.9	43.6
Patients (Number)	**657**	**374**	**110**	**104**	**58**	**159**	**1,462**

Source: Data covering each program's first six months of operations.

Note: The Total column shows the average across the 1,462 patients enrolled during the first six months of operations.

Health Quality Partners had the highest proportions of patients with education contacts; almost all of those enrolled during the first six months received at least one contact for disease-specific education or for explanation about medications. Medical Care Development had among the lowest proportions, again consistent with reports of competing demands on its care coordinators' time.

IV. HOW DID THE PROGRAM AFFECT PATIENTS AND PROVIDERS?

Among the most critical issues for the evaluation of the Medicare Coordinated Care Demonstration (MCCD) are whether the care coordination programs affect patients' behavior and satisfaction and how physicians view the program. Improved patient satisfaction is important because, if the programs are unable to affect the behavior of either patients or providers, the use and cost of Medicare services are unlikely to change. For this report, we have survey data only for an early sample of patients and for a limited number of intermediate outcome measures. Future analyses will analyze each program separately for evidence of effects on a more comprehensive set of survey-based outcomes, as well as for effects on Medicare service use and costs.

We begin this chapter by examining the patients' satisfaction with care coordination services. As part of that analysis, we show the proportion of control patients who reported receiving services similar to those offered by the demonstration programs. We then compare program patients (that is, patients in the evaluation's treatment group) and control patients on their ratings of their overall access to information, their overall access to health care, and the quality of that care. We then compare the two groups on measures of adherence to medication, diet, and exercise regimens.

We also examine the reactions of physicians to various aspects of the programs and assess the physicians' perceptions as to the program's major benefits and drawbacks. These results must be interpreted with caution because they apply to only a limited number of physicians from a subset of the programs.

A. HOW SATISFIED WERE PROGRAM PATIENTS?

For this preliminary analysis, too few observations on individual programs are available, so we analyze the data for the first two months of the survey for all program sites combined to determine whether any early, overall patterns emerge. The results are drawn from the first six programs to begin enrollment, as shown in Table IV.1. Nearly half of the 1,463 observations are from the two largest of the early programs (Carle and CenVaNet).

1. Patients Like the Program

Overall, 88 percent of treatment group members reported that a care coordinator, nurse, or social worker had helped them to arrange or coordinate their health care since they enrolled in the program (see Table IV.2); however, only 71 percent did so before being prompted with the program name (not shown).[9] About 13 percent of the control group reported that they had received such care. Receipt of this type of services by patients in the control group is not surprising, given that other programs, some of which are operated by pharmacy companies, provide disease management services. The relatively low number of competing interventions suggests that future estimates of program impacts should not be affected markedly by control patients receiving services similar to those provided by the demonstration.

[9]Although one might expect close to 100 percent of patients to report receiving help, it is common for Medicare beneficiaries to have difficulty recalling services that they had received. Those who have relatively less serious problems and need little help may have particular difficulty. Other studies of case management programs have reported far lower proportions of study participants reporting that they had received program services. Thornton et al. (2002) reported that only 21 percent of Medicare beneficiaries enrolled in four exemplary care management programs operated by health maintenance organizations knew they had care managers. The proportion acknowledging some receipt of service is remarkably close to the proportion of enrollees in these programs that program records showed had some case manager contact (91 percent); thus a very high proportion of program patients are at least aware that they are receiving an intervention.

TABLE IV.1

PATIENT SURVEY SAMPLE
(Percentages)

	Treatment	Control
Program		
CenVaNet	26.8	25.7
Carle	25.6	27.5
Mercy	17.3	16.8
Health Quality Partners	12.5	11.8
Charlestown	11.8	11.3
Medical Care Development	6.0	7.0
Primary Health Problem		
CHF	31.0	29.0
Coronary artery disease	19.9	20.1
Diabetes	16.7	17.0
COPD	9.8	9.8
Stroke	2.7	2.9
Other chronic problem	19.9	21.3
Proxy	14.0	10.6
Sample Size	**735**	**728**

Source: Patient intake form completed at enrollment.

Note: Percentages for a given question may not sum to 100.0 due to rounding.

CHF = congestive heart failure; COPD = chronic obstructive pulmonary disease.

TABLE IV.2

PATIENTS' SATISFACTION WITH
CARE COORDINATION
(Percentages)

	Treatment	Control
Reported Receiving Help from Care Coordinators**	[735]	[728]
	87.5	12.6
Ratings of Care Coordinators':		
Knowledge About Health Problems	[623]	[85]
Excellent	58.3	57.7
Very good	31.3	32.9
Good	9.3	8.2
Fair/poor	1.1	1.2
Provision of Educational Material on Primary Health Problem**	[616]	[82]
Yes	76.8	57.3
No	23.2	42.7
Ability to Explain How to Improve Diet*	[510]	[61]
Excellent	42.8	32.8
Very good	40.8	44.3
Good	15.1	16.4
Fair/poor	1.4	6.6
Ability to Explain Exercise Needs and How to Meet Them	[530]	[67]
Excellent	40.2	41.8
Very good	39.3	32.8
Good	18.5	17.9
Fair/poor	2.1	7.5
Overall Quality of Help with Self-Management	[613]	[81]
Excellent	51.9	45.7
Very good	33.4	37.0
Good	12.7	16.1
Fair/poor	2.0	1.2
Ability to Coordinate and Organize Medical Care	[468]	[70]
Excellent	46.6	54.3
Very good	36.1	32.9
Good	15.6	12.9
Fair/poor	1.7	0.0

TABLE IV.2 (*continued*)

	Treatment	Control
Help Making Appointments with Physicians	[310]	[54]
Excellent	46.5	53.7
Very good	39.4	37.0
Good	11.9	9.3
Fair/poor	2.3	0.0
Help Obtaining Treatment/Care Patient Believed Was Necessary	[414]	[70]
Excellent	45.2	48.6
Very good	37.9	35.7
Good	15.0	14.3
Fair/poor	1.9	1.4
Most Important Type of Help**	[606]	[82]
Staying in touch	16.8	11.0
Having a caring attitude	12.9	12.2
Explaining terms, diagnosis, treatments, symptoms	7.6	6.1
Knowledge of health problem	6.6	2.4
Providing/explaining educational material	5.5	0.0
Explaining diet and exercise	5.3	4.9
Obtaining answers from physicians	4.0	3.7
Helping take care of self	3.1	1.2
Making appointments	2.5	1.2
Explaining how to take medicines	2.2	4.9
Recommending/arranging community-based services	1.2	4.9
Obtaining proper treatments	1.0	4.9
Helping with paying for non-Medicare services	0.3	0.0
Other	31.2	42.7
Quality of Overall Care Coordinator Experience	[601]	[80]
Excellent	50.4	45.0
Very good	36.8	41.3
Good	11.3	12.5
Fair/poor	1.5	1.3

Source: Telephone survey of beneficiaries conducted by Mathematica Policy Research, Inc. 7 to 14 months after enrollment.

Note: Values in brackets are the number of observations. Percentages for a given question may not sum to 100.0 due to rounding.

*Significantly different from the control group at the .05 level, two-tailed test.
**Significantly different from the control group at the .01 level, two-tailed test.

Overall, program patients were very pleased with the help they received from the demonstration program. To assess satisfaction, each patient was asked to rate his or her coordinator's knowledge about the patient's health problems; the coordinator's ability to improve the patient's diet, explain necessary exercises, and coordinate care with physicians; and the help that he or she received from the care coordinator to make appointments, obtain necessary care, and perform self-management. For each aspect of care coordination in question, between 80 and 90 percent of program patients rated the help they received as either excellent or very good. As a summary measure, 87 percent of program patients receiving services rated the overall quality of their care coordinator experience as excellent or very good.

For educational types of assistance—but not for other types of help—program patients were more satisfied than were control patients who reported receiving care coordination from other some source. Control patients and program patients were equally satisfied with their care coordination and with the help received to gain access to care. However, program patients were significantly more likely to receive educational materials than were control patients who received care coordination, and they were significantly more satisfied with the explanations about diet. Program patients were both more likely to report that the explanations they received were excellent and much less likely to rate those explanations as fair or poor, suggesting that the demonstration programs are providing better education than other care coordination programs.

The two groups' assessments of the most important way their care coordinator helped them differed only slightly although the difference was statistically significant. In both groups, the most frequently volunteered responses were "staying in touch" (17 percent and 11 percent, respectively, for the treatment group and the control group) and "having a caring attitude" (13 percent and 12 percent, respectively).

2. The Program Improves Some Aspects of Patient Care

Comparison of all program patients with all control patients on the overall health care the groups received from all sources combined shows that the programs appear to have improved satisfaction in some areas substantially, but had little effect in others (Table IV.3). We find large increases in patients' understanding about their primary health problem. This finding is consistent with program data suggesting that, during the first six months of program operations, 81 percent of enrollees in the programs received disease-specific or self-care education. Program patients' understanding about their primary health problems, their ability to obtain answers to questions about their health problems, and their ability to obtain appointments for diagnostic tests or procedures were significantly higher than were those of control patients. However, we find no significant effects on either explanations about medication side effects, explanations about laboratory tests, or specialists' recommendations.[10] We do see significant improvement in two of the three care coordination measures: the office staff's lack of awareness about tests or procedures ordered by another physician, and communication among health care providers. The difference between the two patient groups on the third measure (had difficulty dealing with conflicting advice from physicians or nurses) was small and not statistically significant. Thus, we find some evidence that care coordination improved.

Program patients were significantly more likely than control patients to rate the overall quality of their care as excellent. In both groups, the proportion rating their care as fair or poor

[10]The lack of effect on the quality of explanations about medication side effects seems somewhat odd, given that program data recorded by care coordinators suggest that 56 percent of the patients received explanations about medicines. However, the fact that only about 13 percent of control group patients rate these explanation as fair or poor suggests that patients feel that traditional fee-for-service providers (or pharmacists) do an adequate job in this area.

TABLE IV.3

PATIENTS' SATISFACTION WITH CARE
(PERCENTAGES)

	Treatment	Control
Explanations About Specialist Recommendations	[522]	[535]
Excellent	40.0	34.2
Very good	39.1	38.7
Good	14.0	19.8
Fair	4.2	3.9
Poor	2.7	3.4
Explanations About Possible Side Effects of Medications	[660]	[647]
Excellent	27.3	23.7
Very good	36.7	38.2
Good	26.7	26.3
Fair	6.5	9.0
Poor	2.9	2.9
Explanations About What to Expect from Condition	[709]	[696]
Excellent	26.0	21.3
Very good	36.4	38.5
Good	29.9	30.3
Fair	6.1	7.8
Poor	1.7	2.2
Explanations About Laboratory Test Results	[713]	[707]
Excellent	25.4	24.2
Very good	37.6	38.1
Good	30.6	27.9
Fair	5.1	6.9
Poor	1.4	3.0
Understanding of Primary Health Problem**	[689]	[679]
A lot better	37.9	29.9
A little better	13.6	8.7
About the same	48.5	61.4
Ability to Obtain Answers About Primary Health Problem**	[681]	[668]
A lot better	27.3	16.6
A little better	10.6	6.1
About the same	62.1	77.2
Ability to Obtain Appointments for Diagnostic Tests or Procedures**	[660]	[661]
A lot better	19.4	9.8
A little better	9.1	5.3
About the same	71.5	84.9

TABLE IV.3 (*continued*)

	Treatment	Control
Communication Between Health Care Providers About Care**	[695]	[673]
Excellent	41.4	33.4
Very good	39.0	39.5
Good	14.1	18.3
Fair	4.3	6.2
Poor	1.2	2.5
Physician/Nurse Was Unaware of Results of Tests/Diagnostic Procedures Ordered by Another Physician/Nurse*	[654]	[627]
Yes	8.7	12.1
No	91.3	87.9
Had Difficulty with Contradictory/Conflicting Information from Different Doctors or Nurses	[716]	[697]
Yes	9.2	11.1
No	90.8	89.0
Quality of Overall Healthcare*	[730]	[719]
Excellent	47.5	39.8
Very good	39.2	43.5
Good	11.4	14.7
Fair	1.5	1.8
Poor	0.4	0.1

Source: Telephone survey of beneficiaries conducted by Mathematica Policy Research, Inc. 7 to 14 months after enrollment.

Note: Values in brackets are the number of observations. Percentages for a given question may not sum to 100.0 due to rounding.

*Significantly different from control group at the .05 level.
**Significantly different from control group at the .01 level.

was very small (about 2 percent), but nearly half (48 percent) of the program patients rated their care as excellent, compared with only 40 percent of the control patients.

3. The Program Does Have Not a Detectable Effect on Early Patients' Adherence

Even though program patients were very satisfied with the education and care coordination services they received and were more satisfied than control patients with their access to information and services, they were not discernibly more likely to adhere to treatment regimens. adherence, to diet, exercise, and medication regimens are a key program goal for nearly all of the programs. However, the program patients were only slightly more likely to report that they exercised regularly, (by two percentage points) or that they followed a healthy diet (by four percentage points); as Table IV.4 shows, roughly two-thirds of the patients in both groups adhered to these recommendations. We see an even smaller treatment–control difference in the proportion of patients who reported that they had not missed a dose of their prescribed medications during the week preceding the interview. Because roughly 90 percent of the patients in the study reported that they had not missed any doses of their medications during that week, showing improvement on this adherence measure will be difficult.

While these preliminary findings might be viewed as somewhat discouraging, given that many programs have focused on improving patient adherence they are based on the experiences of patients in only 6 of the 15 sites and cover only the first year of program operation. Future analyses will show whether the effects are larger for some programs or some diagnoses than for others, whether they are larger for later cohorts of enrollees who may reap greater benefits from a program's greater experience, and whether they vary with the length of time that patients had been enrolled at the time of interview.

TABLE IV.4

PATIENTS' ADHERENCE TO MEDICATION, DIET, AND EXERCISE REGIMENS

Adherence Measure	Sample Size	Treatment Group	Control Group	P-Value
Ate a Healthy Diet Most or All of the Time in the Past Four Weeks	1,098	72.2	67.7	.10
Exercised Regularly	1,445	65.1	63.1	.44
Did Not Miss Doses of Medication for Target Condition in the Past Week	1,202	90.1	89.6	.99

Source: Telephone survey of patients conducted by Mathematica Policy Research, Inc., May-June 2003.

B. HOW SATISFIED WERE PHYSICIANS?

We also present preliminary data obtained from the first 112 physicians to complete the physician survey. The physician survey is important in the evaluation for gauging the generalizability of the results to settings other than the demonstration sites, and for assessing physicians' acceptance of the demonstration programs. The Evaluation of the Medicare Case Management Demonstration (Schore et al. 1997) and other studies have shown that physician involvement and buy-in are critical to the success of care coordination programs.

This early sample of physicians of program enrollees consisted predominantly of generalist physicians (91 percent internal medicine, family practice, or geriatrics; Table IV.5). The great majority were board certified (88 percent), and they had been practicing for an average of 18 years (with a wide range of 2 to 45 years). Eighty-two percent practiced in group practices of three or more physicians or in clinics. Most were fairly busy, seeing an average of slightly more than 100 patients during a typical week, and most saw substantial numbers of Medicare beneficiaries (43 percent of their caseloads, on average) and adults with chronic illness (55 percent of their adult patients). The majority (68 percent) had had some experience with health-plan-sponsored disease-management or case-management programs prior to their exposure to the MCCD.

The physicians believed that, with respect to their interactions with enrolled patients, the programs had positive effects on their office practices and on their own practice. The majority felt that the programs had reduced their and their office staffs' telephone time, and that the programs also made things easier for their office staff (Table IV.6). Their opinions about program effects on paperwork were more mixed, with 30 percent reporting that the programs reduced paperwork, but roughly 10 percent reporting that they worsened it. (The remaining

TABLE IV.5

PHYSICIAN SURVEY SAMPLE

	Sample Size	Percentages, Unless Noted Otherwise
Primary Specialty	112	
Family practice		56
Internal medicine		33
Cardiology		4
Geriatrics		2
Oncology		2
Endocrinology		1
General practice		1
Other		1
Board-Certified	112	88
If Not Board-Certified, Board-Eligible	14	50
Mean Years in Practice (Range)	111	18 (2-45)
Type of Practice	111	
Three or more physicians		52
Clinic		30
Solo		12
Two physicians		6
Single Specialty Group	92	63
Mean Number of Patient Visits in Average Week (Range)	112	102 (25-380)
Mean Percentage of Patients with Medicare Coverage	112	43 (5-100)
Mean Percentage of Adult Patients with Serious Chronic Illnesses	111	55 (10-100)
Mean Percentage of Patients in Managed Care	109	31 (0-100)
Previous Experience with Disease Management or Care Management Programs	112	68

Source: Telephone survey of primary physicians of treatment group members, administered approximately 12 to 14 months after program startup. The survey was administered only to physicians familiar with the local Medicare Coordinated Care Demonstration program and aware that they had enrolled patients (112 of 147 physicians contacted). These are the first physicians to complete the survey.

TABLE IV.6

PHYSICIANS' PERCEPTIONS OF PROGRAM EFFECTS AND PERFORMANCE
(Percentages)

Physician Practice						
Program's Effect (for Enrolled Patients) on:	Worse	No Difference	A Little Better	A Lot Better	Not Applicable	Does Not Know
Physician and staff telephone time	2	25	38	32	—	3
Office staff workload	2	29	43	21	1	4
Physician paperwork	12	57	25	5	1	—
Physician workload	1	18	51	30	—	—
Physician malpractice risk	1	62	21	4	2	10

Program's Effect on:	Decreased	Stayed the Same	Increased	Does Not Know
Number of Office Visits for Enrolled Patients	29	58	6	6

	No	Yes	Does Not Know
Medically Appropriate Visits (n = 40)	5	93	3

Arranging Services						
Helping Patients Obtain:	Worse	No Difference	A Little Better	A Lot Better	Not Applicable	Does Not Know
Timely appointments with specialists for patients	1	53	27	8	1	11
Expensive medications	—	36	22	25	6	11
Therapies and social work	—	18	39	28	8	6
Services, such as transportation, personal care, meals on wheels	—	14	29	38	4	14

TABLE IV.6 *(continued)*

Patient Education							
Program's Effect on Patients' Adherence to or Improvement in:	Poor	Fair	Good	Very Good	Excellent	Not Applicable	Does Not Know
Taking prescribed medications	0	6	33	37	19	1	4
Following diet	4	13	33	25	10	4	12
Exercising	5	25	31	13	4	4	17
Monitoring own health conditions	1	4	29	31	29	—	5
Making and keeping medical appointments	—	10	29	26	25	5	4
Overall ability to manage health conditions	—	9	31	38	14	4	4

Care Coordination						
Program's Effect on:	Worse	No Difference	A Little Better	A Lot Better	Not Applicable	Does Not Know
Physician coordinating care with other physicians	3	55	31	9	1	1
Patients receiving contradictory information from providers	3	35	36	14	5	7
Patients undergoing unnecessary or duplicate tests	3	42	26	16	—	13
Physician coordinating care with family members and informal caregivers	—	17	38	36	4	5
Resolving conflicts or dealing with difficult family situations	—	33	26	18	12	11
Continuity or fragmentation of care	3	21	35	35	4	4

TABLE IV.6 *(continued)*

Performance of Care Coordinators and Program Staff						
	Fair	Good	Very Good	Excellent	Not Applicable	Does Not Know
Quality of care coordinators' initial home assessments	5	22	25	40	1	6
Ability of staff to monitor and follow up patients	5	20	29	40	3	3

How Often:	Never	Rarely	Sometimes	Frequently	Not Applicable	Does Not Know
Care coordinators helped to detect acute problems	9	31	48	10	1	1
Care coordinators helped to detect emotional problems	19	26	37	18	—	1
Care coordinators helped to detect physical or functioning problems	12	21	43	21	3	1
Physician disagreed with care coordinator on approach to patient's problem	56	37	4	1	2	—

Care Coordinators Ever:	No	Yes	Does Not Know
Arranged for mental health care (of physicians reporting care coordinator ever helped detect emotional problems, n = 90)	61	30	9
Arranged for care for physical or functioning problems (of physicians reporting care coordinator ever helped detect physical or functioning problems, n = 95)	12	87	1
Influenced physician's clinical decision making	45	54	2

	Fair	Good	Very Good	Excellent	Not Applicable	Does Not Know
Care coordinators' overall clinical judgment and competence	5	21	28	42	—	4

TABLE IV.6 *(continued)*

	Fair	Good	Very Good	Excellent
Of physicians who asked care coordinators to address specific patient issues, how well they dealt with those issues (n = 78)	—	12	35	54

	Not Useful	Somewhat Useful	Very Useful
Of physicians receiving feedback or information from care coordinators, usefulness of that information (n = 95)	4	45	51
Usefulness of reports from program, in general	5	56	39

Quality of Care

Program effect on:	Worse	No Difference	A Little Better	A Lot Better	Not Applicable	Does Not Know
Polypharmacy and potential drug interactions	—	31	45	16	3	5
Helping care better meet clinical guidelines or be more evidence-based	2	33	38	23	3	1

Program Effect on:	Not Beneficial	Somewhat Beneficial	Very Beneficial	Does Not Know
Health of enrollees	8	63	25	4

Program effect on:	Stayed About the Same	Increased	Not Applicable	Does Not Know
Enrollees' overall satisfaction with health care	24	69	3	4
Overall quality of care for enrollees	25	73	1	1

	Definitely Not	Probably Not	Unsure	Probably Would	Definitely Would
Would recommend program to patients or colleagues	1	2	4	28	64

Source: Telephone survey of primary physicians of treatment group members, administered approximately 12 to 14 months after program startup. The survey was administered only to physicians familiar with the local MCCD program and aware that they had enrolled patients (112 of 171 physicians contacted). These are the first physicians to complete the survey.

Note: Percentages may not sum exactly to 100 percent because of rounding.

physicians noted no difference.) Thirty-five percent believed that the programs had either increased or decreased enrollees' use of physician office visits, but nearly all saw these changes as medically appropriate. Most physicians did not believe that the programs had had any effect on their malpractice risk, but one-quarter felt the programs had actually reduced it.

Two-thirds of physicians considered the programs to be helpful at arranging services (such as therapy or social work), and support services (such as transportation, personal care, and meals-on wheels) (Table IV.6). Fewer felt the programs had made it a little or a lot easier for patients to obtain specialist appointments in a timely way (35 percent), or for patients to obtain expensive prescription medications (47 percent).

Physicians also thought that the programs were better at helping patients with some aspects of health behavior than with others. They believed that the programs improved patients' adherence to medication regimens, ability to self-monitor, and ability to make and keep medical appointments. They were less positive about the perceived program effects on patients' diets and exercise levels. These results are generally consistent with the insignificant treatment–control differences on adherence measures, except that we find no evidence of improved adherence to medication regimens in the early sample of patients. Most physicians did believe that overall, the programs helped patients to better manage their health conditions.

Physicians were roughly equally divided over whether programs helped them to coordinate their care with the care provided by other physicians, reduce the amount of contradictory information given to patients, or prevent patients from receiving unnecessary or duplicate tests. For these measures, 35 to 55 percent felt the programs made no difference, but 40 to 50 percent felt the programs had made things a little or a lot better. Overall, 70 percent believe that the programs had reduced enrollees' fragmentation of care. Three-fourths of physicians felt that the programs were helping them to interact with their patients' families by coordinating their care

with the care provided by family members. Forty-four percent also considered the programs to be helpful in resolving family conflicts and in dealing with difficult family situations.

Physicians generally rated the care coordinators' clinical skills favorably. As Table IV.6 shows, two-thirds rated the care coordinators' initial home assessments as very good or excellent. A similar proportion (69 percent) rated the coordinators' performance in the areas of monitoring and followup as very good to excellent (with 89 percent giving ratings of good, very good, or excellent). Nearly all of the physicians (95 percent) considered the reports from the program to be somewhat useful (56 percent) or very useful (39 percent).

In the area of patient monitoring, 55 to 64 percent of the physicians believed that the care coordinators sometimes or frequently detected patients' problems (specifically, any acute problems and emotional or physical problems). In the physicians' experience, care coordinators played a much greater role in arranging care for physical or functioning problems than for emotional problems (87 percent versus only 30 percent, respectively, were aware of a care coordinator having made such arrangements). Whether this difference is due to differences in the referral processes for mental health services versus physical and functioning services or to actual performance of the care coordinators is unknown.

About half the physicians reported having their clinical decisions influenced by care coordinators, and 93 percent never or rarely had any disagreements with care coordinators about how to approach patient problems. Seventy percent gave the care coordinators very good or excellent ratings for overall clinical judgment and clinical competence.

The majority of physicians who had asked care coordinators to address specific issues (about two-thirds did so) felt that the care coordinator had dealt well with those issues. Almost all

(96 percent) rated the information they received from the care coordinators about the issue as somewhat or very useful (with half rating it very useful).[11]

Finally, three-fourths of physicians believed that the programs had improved the quality of care of their patients. Two-thirds felt their patients' satisfaction with care had increased. By contrast, perceived positive program effects on polypharmacy and adherence to clinical guidelines were not quite as strong, with 61 percent reporting that the programs had made polypharmacy a little or lot better, and had made care not conforming to clinical guidelines a little or a lot better. Even so, 9 out of 10 physicians believed that the programs produced definite benefits to patient health (with about two-thirds considering the programs somewhat beneficial, and another quarter considering them very beneficial). Ninety-two percent endorsed the programs saying that they would probably (28 percent) or definitely (64 percent) recommend the programs to patients or colleagues.

[11]Physicians who trusted care coordinators enough to ask them to look into specific issues may already have had favorable attitudes toward the care coordinators. Thus, this result is not necessarily indicative of how other physicians would rate these efforts.

V. WHAT ARE THE IMPLICATIONS FOR MEDICARE?

This preliminary synthesis report, based on data from the first year of the demonstration, provides a number of early lessons about the implementation of care coordination programs for Medicare beneficiaries with chronic illnesses. The data required to estimate the impacts of the 15 demonstration programs on the quality of care received by patients or on the use and cost of Medicare-covered services will not be available until January 2005. Here, we have focused on what we have learned about whether such programs can be implemented, how the demonstration programs have structured their interventions, the problems that they encountered during their first year, the types of beneficiaries who have been attracted to the programs, and some early reactions from patients and providers about the program.

A. LESSONS FROM THE FIRST YEAR OF PROGRAM OPERATIONS

Various types of organizations can implement small-scale care coordination programs for beneficiaries with chronic illnesses, but convincing patients to enroll is usually much harder than expected. The participating organizations include commercial disease management vendors, hospitals, academic medical centers, an integrated delivery system, a hospice, a long-term care facility, and a retirement community. The programs operate in 16 states and the District of Columbia; four serve beneficiaries living in sparsely populated rural areas.

The programs targeted patients with a wide range of chronic conditions, with six programs targeting only a single condition, three enrolling patients with less specific problems (for example, high-risk patients identified by an algorithm), and six programs falling between these two extremes. The program patients' most common primary conditions are congestive heart failure (29 percent), coronary artery disease (24 percent), and diabetes (13 percent).

Compared to all Medicare beneficiaries nationally, program patients in the first six programs to start enrollment were substantially more educated and had higher incomes. The programs enrolled relatively few black or Hispanic patients, few patients younger than age 65, and few patients who also were enrolled in Medicaid.[12] However, across all 15 programs, 4 drew a high proportion of beneficiaries older than age 85, and 1 targeted and enrolled a high proportion of younger patients with disabilities.

All 15 of the demonstration programs were operating and implementing their interventions largely as planned, but only 4 met their own enrollment targets for the first year, and only 4 exceeded the minimum first-year target of 686 patients that Mathematica Policy Research, Inc. had set for the evaluation. Several programs enrolled fewer than half their targeted number of patients for the first year, citing initial overestimates of the number of eligible patients from their referral sources, physicians' failure to encourage their patients to enroll, high patient refusal rates, and overburdened care coordinators who had too little time to both recruit patients and serve those already enrolled. The programs that were most successful enrolling patients were those that had close relationships with physicians and those with access to host organization databases to identify potentially eligible patients.

Participants in most programs had higher preenrollment costs than did eligible nonparticipants, but a few programs may be unable to generate net savings even if they were to reduce Medicare costs by 20 percent. Among the 11 programs for which Medicare data were available, preenrollment costs averaged more than $2,400 per month for participants in three programs, but less than $500 per month for two other programs. The programs with low-cost

[12]The racial mix is due largely to the fact that several of the six served areas with very few black beneficiaries. The next Report to Congress will examine reasons for low proportions of minorities in more detail.

enrollees are likely to have difficulty achieving large enough savings to offset their intervention costs. In half of the 11 programs, more than two-thirds of enrolled patients were hospitalized during the year preceding enrollment, and, in most of the 11 programs, the costs for enrolled patients during that year were higher than the costs for eligible nonparticipants. However, one program whose enrollees had preenrollment costs of less than $500 per month enrolled patients with preenrollment costs and admission rates that were markedly lower than those of eligible nonparticipants. It appears that this program enrolled sizable numbers of beneficiaries who did not meet all of the programs' eligibility requirements.

The demonstration ultimately should yield information on what interventions work best, as the 15 programs differed in the aspects of care coordination they emphasized, their links to providers, and their degree of focus on patients' primary conditions. The programs differed in their relative emphasis on four major vehicles for achieving better outcomes for patients: improving patients' adherence to treatment and self-care regimens, improving coordination and communication among providers, improving physician practice, and increasing access to support services. All but 1 of the 15 programs stressed improving adherence and coordination as key objectives, but most devoted somewhat less attention to either getting physicians to change their practices or improving access to support services. Six of the 15 programs used high-tech devices to help to monitor patients; however, in two of these programs, only small subsets of patients were given the devices. All but two programs developed patient education interventions to improve patient adherence. Among the six early programs, efforts to improve communications generally focused on teaching patients how to obtain information from their physicians, although care coordinators in one program primarily contacted the physician themselves to obtain the information for their patients. Program staff reported that the programs have little leverage over physicians, and that the physicians affiliated with their programs generally already were adhering

to guidelines; consequently, only five of the 15 programs issued guidelines or reports to providers indicating deviations from guidelines. Efforts to change physician practice focused mainly on tactfully notifying a patient's primary care physician that a prescribed medication or treatment the patient is receiving was not consistent with guidelines. The programs have limited funds for paying for non-Medicare-covered services, so their efforts to improve access consisted mainly of learning about and helping patients to arrange for services available from other community sources. Only about 10 percent of patients received help with support service arrangement, according to program records.

All the programs recognized the importance of integrating their efforts with those of their patients' physicians, and either their care coordinators and physicians had established links before the programs had entered the demonstration or they made conscious efforts to facilitate the creation of such bonds. Their efforts included (1) inviting physicians to serve on program advisory boards or identifying local opinion leaders as program champions, (2) stationing care coordinators in the same location as the physicians or ensuring that all the program patients for a physician had the same care coordinator, and (3) holding regular meetings between care coordinators and physicians or issuing periodic reports. In 3 of the 15 programs, care coordinators and physicians had preexisting links, and those programs used all three approaches to foster integration. Two programs began operations without any preexisting links, and they adopted only one or none of the approaches to building relationships.

Finally, programs varied in their approach to care coordination, ranging from a narrow but in-depth focus on problems associated only with the targeted conditions to a broader focus encompassing all of the patients' medical conditions, as well as psychological needs. Three programs focused their interventions on the targeted conditions, with little attention to comorbidities or social barriers to better adherence; one program took the opposite approach.

The 11 other programs fall somewhere between these extremes of the continuum. Although the 11 established guidelines for the treatment of the primary targeted conditions, they also devoted substantial attention to dealing with major comorbidities, and they sought ways to address psychosocial barriers as well.

The programs assessed patients in person, but most subsequent contact were by telephone. More comprehensive examination of the six programs that first began enrolling patients (in April 2002) show that they used a variety of assessment tools, and that they differed substantially in the sizes of their caseloads. The six programs had an average caseload after six months of operations of 25 patients per care coordinator, but caseloads for the individual programs ranged from 4 to 52 patients per coordinator. In most cases, patients were typically assessed in their homes, with 23 to 72 percent receiving their initial assessment contacts within the first two weeks after enrollment. Programs that could not begin all their assessments quickly cited competing demands on care coordinators as the primary reason for the delays. The assessments culminated in care plans to fill the gaps in the patients' knowledge and treatment. The plans were developed collaboratively with patients and their families and were shared with physicians. (Some programs required physicians to sign off on the care plans; others simply provided the care plans for the physicians' information.) Most contacts after assessment were by telephone, but one program conducted more than 80 percent of its patient contacts in person.

The earliest programs monitored patients at least monthly but relied little on electronic monitoring. The six early programs established guidelines governing a minimal frequency for monitoring patients but relied on the discretion of their care coordinators to determine whether a given patient should be monitored more frequently. Some programs classified patients by acuity level, with different monitoring frequencies recommended for the different levels. During month 6 after program startup, the number of contacts per patient ranged from 1.1 to 2.9. Only two of

the six programs used electronic monitoring devices, and both did so only for a fraction of their patients; four later-starting programs used such devices extensively. The content of the monitoring calls also varied widely and might cover reinforcement of the educational effort; the patients' progress with self-care and adherence to medication, diet, and exercise regimens; enquiries about symptoms and unmet needs for assistance; and enquiries about routine or emergency service use or changes in physicians' treatment plans.

Two of the first six programs to start up did not establish any systems for learning about their patients' adverse events; instead, they had to rely on the patients for such information. The four other programs were notified in some way by their data systems.

Only one of the early programs made substantial demands on physicians' time. However, all linked each physician with a single care coordinator, who made tactful, patient-specific suggestions when treatment deviated from guidelines. All six of the early programs asked physicians to review potential enrollees for appropriateness for the intervention and expected the physicians to respond to care coordinators' requests to discuss specific patients, but different programs varied in how involved they expected physicians to be in the care planning and other program activities. Two required their physicians' input, two required physicians to sign off on care plans, and two mailed copies of the plans to the physicians but made no other demands. In four of the six programs care coordinators had frequent, informal contacts with physicians. Care coordinators in three of the six programs also met with physicians more formally quarterly or semiannually to discuss their patients. Three programs periodically provided written reports about patients.

Three early programs paid the patients' primary care physicians, either for their attendance at scheduled meetings or through a monthly capitation for each patient enrolled. The three other programs did not pay physicians.

In three of the six programs, care coordinators tried to work collaboratively with the physicians of patients whose care was not consistent with the guidelines to determine whether, and how, to rectify the situation. By contrast, as part of its approach to improving clinical practice, one of the six programs expected its care coordinators to routinely compare care with guidelines, and to contact physicians about discrepancies. (Care coordinators in the other two programs were not responsible for ensuring physician adherence to guidelines.)

Nearly all the early programs devoted a high level of attention to providing patient education about adherence to treatment and self-care regimens. Program-supplied data suggest that 80 percent of patients in the six early programs had contacts with their case managers in which educational issues were addressed, with program-specific rates ranging from 71 to 96 percent. The proportion with contacts to explain medications (33 to 93 percent) or tests (12 to 65 percent) were somewhat lower, but still substantial. Five programs developed their own educational curricula; the other adapted previously published materials. The programs routinely assessed how well the patients were responding to the educational intervention. Two did so by tracking clinical indicators, and two others quizzed their patients. The three other programs relied on less formal conversations between patients and their care coordinators during the monitoring calls. Three programs taught patients how to locate community resources.

The early programs have pleased patients, appear to have increased patients' understanding of their diseases, and appear to have increased patients' satisfaction with care overall, but they have not increased this initial sample's rates of adherence to medication, diet, and exercise regimens. Nearly 90 percent of the first 735 program patients interviewed reported that they had received services from their programs. Of these, 80 to 90 percent rated as very good or excellent the care coordinators' knowledge, ability to explain diet and exercise regimens, and help with self-management and service arrangement. On average, on most measures, these

patients rated the help they received more highly than did the 13 percent of control group members who reported receiving care coordination services from some other source. Although patients cited a variety of factors when asked to identify the most important way in which their care coordinators helped them, "staying in touch" and "having a caring attitude" were the two most frequent ways. Compared with the randomly assigned control group, the treatment group patients reported significantly better understanding of their health problems, better communication among their providers, greater improvements in their ability to obtain answers about their primary conditions, greater ability to obtain appointments for tests and procedures, and better ratings of the overall quality of care they received. The program has had no apparent effect on either the ease of sorting out conflicting advice from providers or the quality of explanations about possible side effects of medications; however, relatively few control group patients reported having these problems, so there was little opportunity for major improvement on these measures.

Despite the positive and sometimes large effects on consumers' satisfaction with aspects of their health care and access to information, and the high level of patient satisfaction with their care coordinators, we see no significant differences between the treatment and control groups on adherence. Treatment group patients were only slightly more likely than control patients to report following a healthy diet or exercising regularly, and they were equally likely to report not missing any doses of prescribed medication during the past week.

Physicians were very satisfied with the program, believed it improves patient care, and would recommend it to patients and providers. Interviews with 112 primary care physicians of program patients revealed that that these physicians felt the program reduced their telephone time, had mixed opinions on whether it increased or decreased the amount of paperwork they or their office had to complete, and influenced the frequency of office visits. Some physicians

believed the program led to more office visits, some thought it reduced visits, but both groups felt the induced changes were appropriate. Physicians rated the care coordinators' clinical judgment and competence highly, and 95 percent found the reports coordinators sent them to be very or somewhat useful. More than half the physicians stated that the care coordinators had detected patient problems that the physicians had not known about, and they reported high levels of satisfaction with the way care coordinators dealt with issues. Half the physicians reported that the care coordinator had influenced their clinical decisions in some cases, and 93 percent rarely or never disagreed with the care coordinators.

Most physicians felt the programs did a good job of obtaining social services for patients, but physicians were less sanguine about whether programs could improve the ability of patients to obtain necessary appointments or prescription drugs. They believed that the care coordinators helped by coordinating efforts with the patients' families, and by reducing the fragmentation of care. Overall, 92 percent would recommend their programs to patients and colleagues.

B. LIMITATIONS AND FUTURE ANALYSES

Given that the programs had been operating only for one year at the most when this analysis began, we are unable to address many of the most important research questions for the evaluation in this preliminary synthesis report. The report provides very limited estimates of impacts on patient satisfaction and adherence, and no estimates at all of effects on key outcomes, such as the use and cost of Medicare services. Furthermore, some of the reported implementation findings are based on a subset of the programs, and the survey results are for only the earliest enrollees in the first six sites to begin enrolling. The results of the patient and physician surveys apply to the six programs combined, with two of the six accounting for nearly half the patient observations. Thus, the findings may well be quite different when the full sample is available.

All of these crucial questions and issues will be addressed in the second synthesis report, which is due in August 2005 (40 months after the first MCCD program began enrolling patients). That analysis will present program-specific estimates of impacts on quality of care, service use, costs, adherence behavior, patients' satisfaction and disease-related limitations, and physician satisfaction. The results presented in that report will be drawn from impact estimates provided in program-specific reports produced between January 2005 and June 2005. The survey estimates will be based on samples of roughly 600 patients from each program, and the outcomes based on claims data will be measured over a one-year follow-up period for patients enrolled during the first 12 months of operations. The analysis also will plot program impacts by calendar month of operations for each program's first 24 months. The report will synthesize the findings from the implementation and impact analyses across the 15 programs to identify likely reasons why some programs had larger effects than did others, and it will assess how impacts vary with patient characteristics. The report will form the basis for a second Report to Congress.

C. THE POTENTIAL FOR IMPROVING PATIENTS' LIVES IS SUBSTANTIAL

Even though we do not yet have any impact estimates that would enable us to conclude that the demonstration programs are having large effects on patients' behaviors or outcomes, these preliminary findings do suggest that such effects may be observed when the full set of data become available for all of the programs. Physicians are responding favorably to the program—an important factor, given the widespread recognition that most care coordination programs are unlikely to succeed without significant cooperation and reinforcement from patients' physicians.

The absence of large effects on the patient-adherence measures may be somewhat discouraging, but it does not imply that the program is having no effect on patient behavior. Relative to control patients, program patients are reporting better access to information and appointments, better communication among their providers, and greater understanding of their

health conditions. Furthermore, the finding that program patients are not significantly more likely than control patients to report eating a healthy diet or exercising regularly may have a positive explanation—it is possible that, in part, the treatment group had higher standards as to what constitutes "healthy" or "regular," as a result of the education they received from the program. Their actual adherence may be better than that of the control group's, but the measure may not be able to reflect this. We will examine more-detailed measures of disease-specific adherence behavior and self-care when the full survey sample becomes available. The reader should also bear in mind that the results of the patient survey reflect primarily the experiences of early enrollees in the two programs with the largest enrollment. In addition, in many cases, behavioral change takes time, and some changes do not occur until patients have experienced an adverse event that makes them recognize the value of adhering to their physicians' or care coordinators' advice.

Finally, we know from conversations with care coordinators that their interventions are making important improvements in the lives of some of their patients. Although the following actual case does not imply that the programs will reduce Medicare costs in the aggregate, or that they will lead to statistically significant improvements in patients' adherence to treatment regimens, they do provide evidence of the programs' potential to do so, and of the real impact that the programs are having for some patients.

> Mr. Jones is a 77-year-old retiree and widower. He has diabetes, coronary artery disease, hypertension, and several other chronic conditions and has been treated for prostate cancer. His leg was amputated above the knee. He suffers from depression as a result of the recent deaths of his wife and brother. He takes 14 medications. Serious exacerbations of his conditions have brought him to the hospital many times in recent years. Mr. Jones had not known about the actions he could take to control his diabetes.
>
> Following assessment, his care coordinator developed a plan to address his most pressing needs: severe abdominal pain from chronic enteritis resulting from radiation therapy; incapacitating pain at the site of his amputation; and depression.

Program interventions included support and education in several areas. The care coordinator provided education on dietary changes to control the enteritis and taught Mr. Jones to recognize symptoms signaling the need to contact his physician before an obstruction developed that would require hospital care. He also was taught how to take pain medication correctly, and he learned that appropriate use would *not* lead to addiction, as he had feared. Mr. Jones was provided with education about diabetes care that covered the importance of testing his blood glucose twice a day, modifying his diet, and performing regular self-monitoring, such as foot examinations.

The program also referred him to a bereavement group at a local hospital. Despite his initial resistance, Mr. Jones found the group so useful that he joined a second one, at his church. In addition, the care coordinator helped him to develop a system to ensure that he took all his medications each day, helped him have his prosthesis adjusted for greater comfort, and encouraged him to join a fitness center (after having a cardiac stress test). After a year in the program Mr. Jones has had only one 1-day hospital admission.

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