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Best Practices in Coordinated Care

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EXECUTIVE SUMMARY

BACKGROUND

To study possible reforms and innovations to the Medicare FFS program, Congress mandated in the Balanced Budget Act of 1997 that the Secretary of Health and Human Services evaluate best practices of coordinated care and design a demonstration project for targeted beneficiaries in the Medicare FFS program. Mathematica Policy Research, Inc. (MPR) was competitively awarded the contract to conduct a review of best practices in chronic illness care coordination and to recommend demonstration design options.

This report describes lessons learned from current best practices in coordinated care as the first step in designing the mandated demonstration programs. A separate report will propose key demonstration design features, including the method of paying for the intervention, financial incentives for programs to generate savings to Medicare, target sample sizes for the demonstration programs, and methods for evaluating them.

Current health care often fails to meet the needs of chronically ill people. Treatment regimens for chronic illness often do not conform to evidence-based guidelines (Large State Peer Review Organization 1997). Care is frequently rushed and overly dependent on patient-initiated followup. Providers typically devote little time to assessing function, providing instruction in behavior change or self-care, or addressing emotional or social distress (Calkins et al. 1991; Clark and Gong, 2000; and Holman and Lorig 1998). Care is fragmented, with little communication across settings and providers (Manian 1999).

A small proportion of chronically ill persons also incurs the large majority of health care costs (Eggert 1988). Furthermore, many unplanned hospitalizations of chronically ill persons appear to be preventable. Thus, preventive interventions targeted to this group might yield sizable overall savings in health care.

Based on these observations, we developed a working definition of what coordinated care is. We also kept in mind the needs and priorities of the Medicare program both to control program expenditures and to make available high-quality health care for its beneficiaries. Thus, coordinated care programs should serve chronically ill persons "at risk" for adverse outcomes and expensive care. They should remedy the above listed shortcomings in current health care for chronically ill people by (1) identifying those medical, functional, social, and emotional needs that increase their risk of adverse health events; (2) addressing those needs through education in self-care, optimization of medical treatment, and integration of care fragmented by setting or provider; and (3) monitoring patients for progress and early signs of problems. These approaches may be able to raise the quality of health care, improve health outcomes, prevent costly hospitalizations and other medical care, and produce program savings.

In seeking to improve the quality of care and reduce medical costs, a number of organizations, including managed care plans, commercial firms, and academic medical centers, have developed programs to coordinate the care of chronically ill persons. These programs are generally not available, however, to beneficiaries in the Medicare fee-for-service (FFS) program, which covers acute care only.

METHODS

We took a two-phase approach to identifying best practices in coordinating care--we identified as many successful programs as possible, then interviewed a selected subset in detail to assess the reasons for their success. We restricted our search to actual (not proposed) programs with evidence of reductions in hospital admissions (the costliest Medicare-covered service) or in total medical costs, because programs without such effects are unlikely to generate sufficient savings to cover the cost of the intervention. We also limited our search to programs serving adults with chronic, systemic illness or providing true care coordination (not, for example, medical devices or programs for wound care).

We searched extensively for both published and unpublished programs. To find published programs, we used an electronic literature search and scanned new issues of relevant journals. A public solicitation of programs started with HCFA's publication of a notice in the *Federal Register.* We also canvassed experts, followed trade publications, placed notices in professional and trade journals, created a Web page, broadcast notices to relevant e-mail discussion groups, and sent mailings to professional and trade organizations. We developed instruments to rate programs on the size of their effects on rates of hospitalization or total medical costs, the credibility of the evidence for those estimates, the size of any effects on patient well-being, and the process of care.

Of the 157 programs that volunteered to provide us with all the necessary information, 67 reported reductions in hospital use or cost and met the other criteria for inclusion. Twenty-two (33 percent) of these were from a hospital or hospital-based health system, 14 (21 percent) from an academic medical center, 13 (19 percent) from a commercial vendor, 14 (21 percent) from a health plan or managed care organization, 1 (1 percent) from a group practice or multispecialty group, and 3 (4 percent) from other organizations like home health agencies or community health centers. Based on their ratings, a subset of 24 programs were selected for further interview.[1] An additional set of three programs with good ratings on the process of care coordination, but *without* hospital use or cost impacts was also interviewed for a further understanding of what factors might have led to their lack of success. Two of the 27 interviewed programs were then excluded: a group clinic program that was not a true care coordination program, and a consulting program that did not provide direct services to patients. Finally, four published programs with zero use/cost impacts, whom we did not interview, were also included, making a final group of 29 programs for detailed study.

Using semistructured interview protocols, two study team members with extensive experience in the case management field conducted comprehensive telephone interviews with senior program

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[1] One of the interviewed programs was included only on the basis of impacts on hospital use/cost from an earlier version of the program. A recent evaluation of the current version of the program shows a lack of hospital use/cost impacts.

staff. The interviews sought the details of programs' care coordination practices and elicited the views of program staff members concerning reasons for their success or lack of success.

FINDINGS

The Care Coordination Programs Accomplished Three Steps

Programs started by targeting one of two broad categories of chronically ill people: (1) those at "high risk" for suffering adverse, expensive health outcomes; or (2) those whose main health problems were certain specific diagnoses.

All the programs went through a three-step process with each patient:

1. ***Assess and Plan.*** Identify all important problems and goals. Produce a clear, practical plan that addresses these problems and lists specific goals.[2]

2. ***Implement and Deliver.*** Operationalize the plan and deliver the interventions.

3. ***Reassess and Adjust.*** Determine whether the interventions are working and, if they are not, adjust the plan.

Although care coordination does not really occur in discrete steps and tasks, and the steps actually occur simultaneously or blend into each other, we found it conceptually useful to divide up the process this way. The first step encompasses such activities as initial patient assessment, defining problems and goals, choosing interventions to meet each problem and goal, and writing down a plan of care. The second step covers the domains of patient education, service arrangement, and coordination with providers. The third step entails regular evaluation and monitoring of whether the plan of care developed in step one, and its execution in step two, are achieving the intended goals.

Quality improvement is another important program feature. We did not list it among the three steps, however, because it does not function at the individual-patient level. Ideally, programs should engage in efforts to continually improve their performance.

Each Step Has a Number of Component Tasks

The successful completion of each step requires the performance of several smaller tasks. For example, in step one, merely uncovering problems in the initial assessment without having available a number of proven, effective interventions to address those problems will do the patient no good.

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[2] This first step could and probably should also incorporate the patient's strengths or assets for staying well, but in the interviews, program staff spoke mostly of ways of uncovering and addressing problems.

Thus, we broke each step down further into a number of component tasks. Step one, Assess and Plan, has four tasks:

1. ***Uncover all important problems.*** These are the problems that can keep the patient from better health and lead to unplanned hospitalizations. These problems vary for each patient.

2. ***Address all important problems and goals.*** Every important problem and goal should have a plan and an intervention or interventions to address it.

3. ***Draw from a comprehensive arsenal of proven interventions.*** A care coordinator must have a broad array of appropriate, proven interventions available in order to choose the best ones to meet a patient's needs.

4. ***Produce a clear, practical plan of care, with specific goals.*** The first step concludes with a written, individualized plan of care. It is important that all concerned--patient, care coordinator, primary care physician (PCP)--have a common, agreed-upon set of goals for the patient, and when and how the patient is going to achieve them.

In the second step, Implement and Deliver, the care coordinator must implement the plan and deliver the services outlined in the plan of care. Care coordinators provide services of care coordination and communication (embedded in the first and second tasks), patient education (third task), and oversight of the care plan and assurance that interventions happen as planned (fourth task). The care coordinator must:

1. ***Build ongoing relationships with the PCPs and with other providers.*** This task enables care coordinators to coordinate care and facilitate communication among providers. Also, programs that fail to engage the physician may be limited in the degree to which they can address the medical aspects of care coordination.

2. ***Build ongoing relationships with patients and families.*** The foundation for this relationship is often laid during the initial assessment in the first step.

3. ***Provide excellent patient education.*** This intervention must be part of every plan of care. Programs must teach patients crucial self-care skills, such as proper diet for their condition, medical compliance, self-monitoring, emergency action plans, and skills to cope with the stresses of chronic illnesses.

4. ***Make certain that planned interventions get done.*** This task involves monitoring to make sure each intervention gets done.

Finally, the third step, Reassess and Adjust, has five tasks:

1. ***Perform periodic reassessments.*** The care coordinator must contact patients on a regular basis to make sure they continue to progress and have not encountered new problems.
2. ***Be accessible.*** Patients must have an easy way to reach a care coordinator at all times.
3. ***Nurture the relationship with PCPs and providers.***
4. ***Nurture the relationship with patient and family.***
5. ***Make prompt adjustments to the plan of care as needed.*** If the reassessment in the first task reveals a lack of progress, the plan of care may need to be changed. Several interventions may have to be tried and discarded before a successful solution is discovered. Changes in the plan of care also need to be made promptly, sometimes even urgently. Patients' level of risk for complications may change, necessitating a change in follow-up frequency.

There Were Two Main Types of Care Coordination Programs, Each Serving Different Populations of Patients

The two main types were non-disease-specific programs ("case management programs") and disease-specific programs ("disease management programs"). The two main types of programs differed in the patients they served and the tactics they adopted to accomplish the three steps and their component tasks.

Case management programs target "high-risk" patients--those at high risk of suffering costly hospitalizations and adverse health outcomes because of complex social and medical vulnerabilities. These high-risk patients tend to have diverse combinations of health, functional, and social problems. We studied 11 case management programs with high process-of-care scores and evidence of impacts.

Disease management programs target patients whose main health problem is a single diagnosis. Even though most patients also have comorbid conditions, patients whose main problem is a specific diagnosis tend to have a relatively standard set of needs related to that diagnosis. The description of disease management programs is based on seven disease management programs with high process-of-care scores and evidence of impacts.

Both sets of programs in our study had significant experience in coordinated care. The average and median ages of the case management programs were 4 years and 3.5 years, respectively. The average and median ages of the disease management programs were 3.3 years and 3 years, respectively. Program staff described an initial learning curve and the need to make adjustments over the years. In both types of programs, care coordinators were nurses with at least a bachelor's degree in nursing. Some of the case management programs relied on advanced practice nurses (master's-prepared nurses).

Approaches of Case Management Programs to the Three Steps

For high-risk patients, the first step (Assess and Plan) included a comprehensive initial assessment that covered a broad set of domains, ranging from medical (such as diagnoses and medications), to functional (such as activities of daily living), to social (such as caregiver burden or availability of transportation), to emotional (such as depression or loneliness).[3] Assessments were done in person and often included a home evaluation. With patients' permission, case managers consulted with PCPs and family members, and often with others involved with the patient as well (nurses, physical therapists, sometimes even neighbors or apartment managers). The assessment concluded with a clear, written plan of care that listed individualized problems, goals, and interventions. Interventions were varied and often included referrals to community services or resource organizations.

In step two, case managers implemented the plan of care and delivered services. In order to enable care coordination and facilitate communication, case managers strengthened their relationships with patients and families, as well as with PCPs. In most programs, there was no requirement that patients switch PCPs in order to receive case management services or that they be locked into a restrictive provider network.[4] All programs provided extensive patient education. Case managers taught patients in the following areas: symptom identification and management; self-monitoring; avoidance of triggers of clinical worsening; reduction of emotional distress; appropriate activity level; compliance with medications, diet, and medical followup; appropriate use of emergency and PCP office care; ways of interacting with physicians; advanced directives; and health care power of attorney. Since patients tended to have different combinations of problems, education was highly individualized.

Finally, in step three, all programs followed up with patients by telephone or through home visits to make sure they were progressing as planned and to catch incipient problems early. The frequency and method of monitoring was generally left to the discretion of the case manager. Some programs discharged patients when case managers felt they had stabilized, and others kept patients in the program but monitored them less frequently and by telephone.

Case management programs' quality improvement efforts were variable. A few came close to true continuous quality improvement by regular monitoring of key indicators with feedback to staff, but many relied more on ad hoc or retrospective analyses of cases ending in untoward events such as avoidable hospitalizations.

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[3] Some programs first assessed patients' risk level (the patients' risk of requiring costly care and suffering adverse events) and performed less thorough initial assessments for low-risk patients. In this report, we focus on the process of care for high-risk patients.

[4] There were a few "team programs" in which PCPs and case managers were all on the same case management team. Thus, only patients of the designated PCPs received case management services.

Rural Case Management Programs Functioned Similarly but Were Constrained by Geography

The four rural programs we identified, all case management programs, looked similar to the nonrural programs. However, rural programs felt that their case managers' close ties to and knowledge of the community were especially critical to gaining patients' trust and finding ways of getting things done. Travel distances placed important constraints on case managers, limiting their caseloads, forcing them to expend energy on transportation arrangements, and making it difficult for them to forge collaborative relations with outlying physicians.

Approaches of Disease Management Programs to the Three Steps

Step one for the disease management programs involved an initial assessment of a narrower set of domains and a more standardized plan of care than for case management programs. Domains assessed included knowledge of the specific disease; self-monitoring skills; health status; smoking and alcohol consumption; compliance with medication, diet, and exercise recommendations; stress management and coping skills; depression; readiness to make behavioral changes; and conformance of the medical regimen with established guidelines on quality care. In several programs, patients' problems and goals were selected from standard templates, so that problem and goal lists were individualized, but within a range set by the templates. In all programs, the initial assessment and the care planning were tied to standard national guidelines of care for the particular disease. There was less emphasis on consulting a wide range of sources in the initial assessment, and less emphasis on arrangement of services to community agencies as part of the plan of care. Thus, disease management programs relied less heavily on the discretion of their care coordination staff.

In step two, the disease management programs stressed building relationships with patients, providing excellent patient education, and making sure medical care conformed to established guidelines. Again, in nearly all programs, the disease management programs worked *with* patients and their PCPs, and patients were not required to see a special set of doctors. Patient education tended to be more standardized than in case management programs, and programs evaluated more systematically the quality of the education provided.

In step three, as in the first two steps, programs generally had more explicit guidelines than did the case management programs for the minimum frequency of followup, and there was less reliance on the discretion of disease care managers. Disease care managers could exceed the minimum number of visits, however, if they felt the patient needed it. Compared to the case management programs, the disease management programs made more use of technology to monitor patients, such as software that prompted disease care managers on currently due and overdue interventions, and Interactive Voice Response (IVR) systems that allowed patients to make daily reports of their vital signs and symptoms using a touch-tone telephone. Some of the programs discharged their patients, while others did not discharge them but instead moved them to lower intensities of monitoring. Programs that never discharged their patients pointed out that chronic conditions such as diabetes and heart failure are incurable, and that it is human nature to lapse into old behaviors.

Disease management programs' quality improvement efforts tended to be more systematic than those of case management programs. The greater computerization of these programs facilitated regular reporting of process and outcome indicators.

Common Features of Case Management and Disease Management Programs

Despite the differences outlined above between the two types of programs, there were a number of common features. All programs had been in existence for a number of years. In all programs, care coordinators were nurses with at least a bachelor's degree in nursing, and some case management programs had master's-level nurse case managers. All programs went through the three-step process with each patient. All programs also completed certain component tasks within each step: producing a written plan of care at the end of step one, establishing an ongoing relationship with patients and providing patient education and monitoring in step two, and periodically reassessing patients as part of step three. All the disease management programs built their programs around national evidence-based or consensus-based guidelines.

Finally, all programs seemed to have a proactive outlook, to view care coordination as a preventive activity. They saw their mission as one of providing services to patients in the present to prevent adverse health outcomes and hospitalizations in the future. Thus, arranging for supportive services in the home and teaching patients to monitor and take care of themselves are examples of efforts to keep problems from developing in the first place. Periodic reassessment and adjustment of the care plan are meant to catch any problems as early as possible and deal with them before they become severe.

LIMITATIONS AND STRENGTHS OF THIS STUDY

Limitations

Our study relied on data reported by the programs we evaluated. We have no independent means of verifying this process and impact information. However, information from unpublished programs did not seem to differ markedly or systematically from that of published programs. The interviews with program staff were also conducted by two objective interviewers with extensive case management experience who sought to obtain an accurate picture of program operations. Furthermore, our observations on the three major steps, the important component tasks, and the programs' proactive philosophy reflect the experience of virtually all of the programs. Finally, the conclusions are supported by evidence from non-interviewed programs and the small number of programs we studied with zero use/cost impacts, and are consistent with the conclusions of other authorities on chronic illness care.

We also did not have a census or a random sample of programs. Our sample consists of programs that volunteered to submit data, and a significant number of programs we identified or were aware of did not respond. It excludes programs that lacked data on impacts on hospital admissions or total medical costs. Although including more programs may have uncovered additional examples of ways to accomplish the three steps, it seems unlikely that additional programs would have changed our conclusions on the basic three steps.

A number of programs we reviewed had managed care or integrated delivery system features that might not translate to a Medicare FFS setting, such as health plans' contractual leverage over providers or programs' access to health plan administrative databases. These features were not universal across the programs, however, and it appears care coordination programs can improve patient outcomes without them.

Finally, because of the study design, there were a number of issues we could not address. There was not enough variation in certain features, such as financial incentives for providers or the adequacy of primary care, for us to discern what the effect of their absence would be. Given programs' lack of data on operating costs, we also could not assess program cost-effectiveness. By focusing on programs with reduction in hospital use, though, we selected programs that have the potential to be cost-effective.

Strengths

A noteworthy feature of our study is the weight given to evidence. We included only programs with reported impacts. We considered not only the size of programs' reported impacts, but also the quality or credibility of program evidence. We are unaware of previous reviews that have limited themselves to programs with measurable impacts or have ranked programs by the quality of their evidence.

Our study also maintained a practical focus on programs that stand a reasonable chance of being cost-effective because they have reduced use of expensive health care services. Programs that demonstrate improvements only in clinical processes of care are an important contribution, but unless they can also be shown to save at least as much money as they cost, they would only exacerbate Medicare's projected financial deficits.

We also set forth a working definition of what "care coordination" is. These considerations excluded two kinds of so-called "case management" programs. The first kind, developed mainly by hospitals, has a primary goal of shortening inpatient hospital stays. The second kind, seen mostly in managed care plans, seeks to find the least expensive alternative among covered treatments or benefits for a given clinical situation. Neither type of program tries to meet the needs of chronically ill people that current health care fails to address, and neither type of program typically takes the long-range proactive approach of intervening to avert poor outcomes in the future.

Our study had a broad scope. We considered both case management and disease management programs and pointed out useful distinctions and similarities. We noted that "high-risk" patients and patients with a primary disease have different needs and that these contrasting needs shape the details of how programs approach the three steps. Earlier studies have examined either case management programs or disease management programs exclusively, or they have grouped them together without recognizing potential differences. Unlike other studies that have restricted themselves to the managed care setting, our study also included programs regardless of setting or sponsor.

Finally, ours was an empirical approach. We did not start with any detailed preconceptions of what features programs must possess or any specific models that such programs must follow. Thus, our conclusions are broadly applicable to a variety of programs and settings.

Implications for Care Coordination in General

The care coordination programs we studied appear to be providing to chronically ill people important services that they currently cannot obtain in the traditional U.S. health care system. Although providers in the current system do provide some care coordination services, they generally do not offer the breadth or depth of services we found in these programs: comprehensive multidimensional assessment of medical, functional, and psychosocial needs; arrangement of community services; coordination across providers; intensive health education and support for lifestyle modification; and methodical tracking of patients' progress between office visits.

There appear to be two main populations of chronically ill patients and two corresponding and equally important types of programs that have evolved to serve them: case management and disease management programs. Case management programs tend to serve a smaller group of complex, medically or socially vulnerable "high-risk" patients. They carefully assess each patient's distinct set of problems and goals to develop highly individualized plans of care. Disease management programs tend to serve a larger group of patients whose main problem is a single chronic disease. These patients generally have similar primary needs, and programs can take a more standard approach with each patient.

Even within each broad category of program, there were many effective ways of coordinating care. In part, the wide variations in approaches reflected underlying variations in the characteristics of patients served. Whether a successful program included or omitted a specific strategy seemed to depend on the barriers to health (or assets for wellness) of that program's patient population. Thus, assessment of a program's approach requires an accurate picture of a program's patient population and its needs.

Our study suggests that incremental approaches to improving chronic illness can succeed. There is nothing in the three steps or the overall proactive stance that requires any organizational or structural change in the health care system. The great majority of programs in our study did not require physicians to acquire new staff or equipment or to reorganize their practices. Programs did not require patients to be "locked in" to a predefined network of providers. The programs did not take chronically ill patients away from their PCPs.

Implications for the Demonstration

Our study suggests that a demonstration in FFS Medicare of coordinated care programs similar to the ones we studied should be feasible and appears to have a reasonable chance of being cost-effective. Given the focus of the demonstration, selected programs will have to target populations that are currently of the highest importance to the Medicare FFS program. In addition, based on common themes and features in the programs studied, we make the following five recommendations for features of demonstration programs:

1. Programs should follow the three steps (Assess and Plan, Implement and Deliver, Reassess and Adjust) for all enrolled patients.
    - Step one should conclude with a written plan of care.
    - Step two should include the establishment of an ongoing care coordinator-patient relationship, and the provision of excellent patient education.
    - Step three should include periodic reassessment of patients' progress.
2. Programs should have express goals of prevention of health problems and crises, and of early problem detection and intervention (a proactive approach, in other words).
3. Disease-specific programs should incorporate national evidence-based or consensus-based guidelines into their interventions.
4. Care coordinators should be nurses with at least a bachelor's degree in nursing.
5. Programs should have significant experience in care coordination and should have evidence of having reduced hospital use or total medical costs.

Implementation of a care coordination demonstration in FFS Medicare also raises a host of difficult design issues, which are addressed in a separate demonstration design report. Our findings suggest that care coordination holds the potential to reduce health care utilization while maintaining or improving the quality of care for chronic illness within the existing health care system. What remains to be seen in the demonstration is whether care coordination programs like the ones studied can achieve the same medical cost savings and quality impacts when implemented in the general Medicare FFS setting, and whether the savings will at least equal the costs of the intervention.

I. INTRODUCTION

It has long been recognized that, in most populations, including the Medicare population, a minority of chronically ill people account for the bulk of health care expenditures (Eggert and Friedman 1988). Furthermore, the traditional health care system, oriented to acute care, does not always meet the needs of those with chronic illness. Private insurers (both managed care and indemnity plans), as well as commercial firms and academic medical centers, have sought to reduce medical costs and improve the quality of care by developing a variety of programs, often called "disease management" and "case management" programs, to coordinate the care of chronically ill persons.

The Medicare program faces significant challenges. Its costs have steadily and rapidly increased in recent years, its number of beneficiaries is projected to grow substantially larger, and there are concerns about its long-term solvency. Medicare's fee-for-service (FFS) program represents nearly 90 percent of all Medicare spending, and is likely to remain for some time the dominant form of Medicare coverage for beneficiaries. Recently, there have been calls for Medicare FFS to consider adapting some of the chronic illness programs developed in the private sector (National Academy of Social Insurance 1998; National Economic Council and Domestic Policy Council 1999; and Fox et al. 1998). However, hard evidence on whether these programs work, or which work best, is limited.

To study possible reforms and innovations to the Medicare FFS program, Congress mandated in the Balanced Budget Act of 1997 that the Secretary of Health and Human Services evaluate best practices of coordinated care and design a demonstration project for targeted beneficiaries in the Medicare FFS program. Mathematica Policy Research, Inc. (MPR) was competitively awarded the contract to conduct the review of best practices in chronic illness care coordination and to recommend demonstration design options.

There does not seem to be a clear, universally accepted definition of coordinated care for chronic illness. The various concepts of coordinated care that have been advanced, however, seem to reflect the convergence of two observations. The first is that many, if not most, persons with chronic illness receive neither high-quality health care nor care that meets their needs. People with chronic illness require early detection of functional impairment; prevention of exacerbations and complications; proven, evidence-based treatments; support for patient self-management; and help with the emotional and social tolls of chronic illness (Wagner 1996). There is anecdotal and quantitative evidence, however, that the treatment of persons with chronic illness often does *not* conform to evidence-based guidelines (Large State Peer Review Organization Consortium 1997). Current health care is frequently rushed and overly dependent on patient-initiated followup. Providers devote little time to assessing functioning, providing instruction in behavior change, or addressing emotional or social distress (Calkins et al. 1991; Holman and Lorig 2000; and Clark and Gong 2000). Care is typically fragmented, with little communication across settings (for example, hospitals, nursing homes, and outpatient offices) and providers (including primary care physicians, specialist physicians, home health nurses, physical therapists, and other medical professionals) (Manian 1999). The result is that the health and functioning of patients with chronic illness suffers.

The second observation is that a small proportion of chronically ill persons incur the large majority of health care costs, and that many unplanned hospitalizations of chronically ill persons appear to be preventable. The concentration of health care expenditures in this small group of patients raises the possibility that preventive interventions targeted to them might yield substantial cost savings (Eggert and Friedman 1988; and Forman and Kelliher 1999). This possibility is strengthened by most clinicians' experience that many hospitalizations of chronically ill people appear to have been avoidable, if only early signs of decompensation had been diagnosed and treated, appropriate evidence-based care provided, drug reactions or interactions detected and managed, or adequate instruction on self-care and prevention provided to patients and families (Chin and Goldman 1997; Vinson et al. 1991; and Col et al. 1990). Furthermore, for the elderly, hospitalization are not only a matter of increased costs, but can often themselves lead to a decline in health and function (Creditor 1993), and we believe most elderly patients prefer to avoid hospitalizations whenever possible.

Considering the above observations, and bearing in mind the Medicare program's long-term needs to contain costs and make high-quality health care available for its beneficiaries, we then developed our own working definition of coordinated care. Coordinated care programs, by our definition, are those that target chronically ill persons "at risk" for adverse outcomes and expensive care and that meet their needs by filling the gaps in current health care. They remedy the shortcomings in health care for chronically ill people by (1) identifying the *full* range of medical, functional, social, and emotional problems that increase patients' risk of adverse health events; (2) addressing those needs through education in self-care, optimization of medical treatment, and integration of care fragmented by setting or provider; and (3) monitoring patients for progress and early signs of problems. Such programs hold the promise of raising the quality of health care, improving health outcomes, and reducing the need for costly hospitalizations and medical care.

This report details the results of our study of programs of care coordination for chronic illness. In it, we describe our process for identifying "best practices," the programs that we studied, and the lessons that we have learned. We conclude with general comments on care coordination and discuss implications for the demonstration.[1] A forthcoming report will propose key demonstration design features, including the method of paying for the intervention, financial incentives for programs to generate savings to Medicare, target sample sizes for the demonstration programs, and methods of evaluating the programs.

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[1] This project also included a solicitation of comments from the public and from the care coordination community on the demonstration design and on care coordination in general. Appendix A contains a summary and analysis of the public comments we received.

II. METHODS

The goals of our search for best practices were to assemble the largest possible sample of care coordination programs that showed plausible evidence of success, and then identify a small number of programs we could study in greater depth. As detailed in this chapter, we scored programs along two major dimensions: (1) overall impacts (as measured by the size of program impacts and the quality of the evidence for those impacts), and (2) relatively crude measures of the process of care coordination. We felt that three types of programs would hold the best lessons for care coordination: (1) programs that scored well on the process measures and had large, credible impacts (high-process, large-impact programs); (2) programs with lower process scores that still achieved large, credible impacts (low-process, large-impact programs); and (3) programs with strong process scores yet little or no impact (high-process, small- or zero-impact programs). For the final group of programs for in-depth study, we had originally planned to select primarily high-process, large-impact programs, but also to include a few programs from the low-process, large-impact and the high-process, small- or zero-impact categories.[1] A number of challenges lay in the details of deciding what types of programs to include in our initial search, developing measures to rate programs on the evidence of their impacts and processes of care coordination, finding potential programs, collecting data from programs, and selecting and drawing lessons from the programs that were studied in depth.

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[1] However, as we discuss in Section F, we later had to modify this plan, because we detected few systematic differences in the process indicators between programs reporting large impacts and those reporting small impacts. This was not surprising, given the large confidence intervals around the estimates, the different target populations and length of followup, and different outcome measures.

A. ELIGIBILITY CRITERIA

Our criteria for programs to be included in the study reflected both our desire to be as comprehensive as possible and our practical policy focus on the Medicare program. We developed the following six criteria:

1. Programs must show quantitative evidence of reductions in hospital admissions, or hospital costs or total medical costs per period of time (for example, per quarter or per year, not just per single hospitalization).[2]

2. Programs must be operating or have operated in the past. We wanted to study only real, functioning programs, not proposed programs or theoretical models of care coordination.

3. The study (for the programs from the literature) must have been completed within the past 10 years, and it must be in English.

4. Programs must serve adults (age 19 or older) and not target obstetric or postpartum populations.

5. Programs must serve patients with chronic, systemic illness. For example, programs targeted to wound healing, postoperative recovery, or ocular conditions would not be included.

6. Programs must provide care coordination, as defined in Chapter I. Thus, for example, we excluded suppliers of medical devices or equipment only, interventions that relied primarily on some version of the traditional office visit, and interventions that were exclusively patient education.[3,4]

We had several reasons for the first two criteria. First, in light of earlier programs that failed to produce effects, we sought to study only those programs with credible evidence of effectiveness.

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[2] From here on, we refer to this composite outcome as “hospital use/cost impacts.”

[3] This criterion, in fact, excluded two programs from published articles that we had discussed in an earlier, interim report (Chen 1999).

[4] Early in the study we had also excluded programs that served nursing home residents only, thus excluding a few programs. Much later in the study we did decide to include such programs, but by that point it was too late to study any of the originally excluded programs in any depth.

Second, to be cost-effective, any care coordination program in Medicare fee-for-service (FFS) must be able to reduce hospital admissions, the largest single Medicare expenditure. Because Medicare pays hospitals per admission, programs that merely reduce hospital length of stay will not reduce Medicare payments.[5] Programs that reduce only the use of other health care services, such as physician or emergency room visits, are unlikely to save Medicare enough money to cover program costs. We did not require estimated impacts to be statistically significant; doing so would have been excluded a number of promising programs. Sample size, however, was a factor in our assessment of the quality of the evidence for impacts (see Section B.1.a).

The remaining criteria further refined the type of programs we wished to include. Criterion three limited the study to fairly recent programs, and four through six defined the types of patients served and refined what we meant by "coordinated care."

For two reasons, we did not use program cost or cost-effectiveness in the inclusion criteria, and concentrated instead on program effectiveness. First, program costliness can be modified through economies of scale or other economies; thus, even an expensive but effective pilot program could be made to be cost-effective. Second, we anticipated (correctly) that many programs would have poor or no data on their operating costs. Thus, in the context of this report, "successful programs" refers to programs that are successful in reducing hospital admissions/costs or total medical costs--whether these programs are actually cost-effective is unknown.

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[5] In fact, such programs could potentially increase total medical costs by substituting other types of care for hospital days.

B. SCORING PROGRAMS

We developed criteria to score programs along two critical dimensions: (1) programs' evidence of impacts on outcomes, and (2) programs' process of care coordination.

1. Evidence of Impacts

In rating programs' evidence of impacts, we considered both the quality of the evidence and the magnitude of the impacts.

a. Quality of Evidence

We rank-ordered different ways in which programs could measure their impacts. How program impacts are measured determines the extent of our confidence that the reported impacts are valid and accurate estimates of the program's effects. A large study with random assignment constitutes evidence of the highest quality, whereas small, biased pre-post and comparison group studies constitute evidence of the lowest quality. Table II.1 displays the six-level ranking, which depends mainly on the study design (randomized, pre-post, or comparison group), but also on sample size and the potential for bias.

b. Impact Size

We first developed criteria for categorizing the size of hospital use/cost impacts and, separately, the size of patient outcome impacts. For hospital use/cost impacts, we picked the tertiles of the observed distributions to define impacts as "small" (reduction in hospital admissions ≤34 percent or in total costs ≤26 percent), "medium" (reduction in hospital admissions 34 to 59 percent or in total costs 26 to 43 percent), or "large" (reduction in hospital admissions ≥59 percent or in total costs ≥43

TABLE II.1

CRITERIA FOR QUALITY OF EVIDENCE SCORE

	Design		
	Randomized	Pre-Post	Comparison Group
6	Random assignment of individuals to treatment and control groups; ≥200 cases in each group		
5	Random assignment of individuals, 50<n<200 or Random assignment of clusters, with ≥3 clusters in each group and overall n≥100 for each group	Carefully conducted study, with no probable bias in preintervention mean as an estimate of what would have occurred in the absence of the intervention. History of stable use by the group prior to the intervention. Selection of cases not based on hospitalization or particular incident (unless the incident is explicitly excluded from the calculation of preintervention means). Sample size ≥200	Carefully matched comparison group with no apparent biases (similar composition of patients, no likely preintervention practice pattern differences, data supporting validity of comparison group as indicator of what would occur to treatment group in absence of interventions); n≥200 per group
4		Carefully conducted study; 100<n<200 or No history of consistently high use prior to intervention, but no probable bias of significant magnitude; n≥200	Carefully conducted study; 100<n<200 or Less documentation on preintervention similarity of treatment and comparison groups, but no apparent biases; n≥200 per group
3	Random assignment of individuals; n<50 per group or Random assignment of clusters with <3 clusters in each group or ≥3 clusters but n<100 per group	Carefully conducted study; n<100 or No history of consistently high use prior to intervention, but no probable bias of significant magnitude; 100<n<200	Carefully conducted study; n<100 or Less documentation but no apparent bias; 100<n<200 per group

TABLE II.1 *(continued)*

	Design		
	Randomized	Pre-Post	Comparison Group
2		Probable bias leading to some overstatement of effects or no history of consistently high use prior to intervention and n<100	Probable bias leading to modest overstatement of effects or Little documentation and n<100 per group
1		Likely substantial overestimation of effects due to large inherent bias	Likely substantial overstatement of effects

percent).[6] Because "patient outcome impacts" included such a wide range of outcomes (from patient satisfaction to physiologic measurements[7] to percentage of diabetic patients receiving eye exams to death), we used somewhat arbitrary ranges for the three impact categories: "small" (impacts 1 to 10 percent or no impacts reported), "medium" (impacts 11 to 19 percent), and "large" (impacts ≥20 percent).

After categorizing the sizes of each type of impact, we combined them into overall impact categories of small, medium, and large (Table II.2). Reflecting again our need to find programs likely to be cost-effective in Medicare FFS, we gave somewhat greater weight to hospital use/cost impacts. Thus, a program with large use/cost impacts but small patient outcome impacts was assigned a large overall impact, whereas a program with large patient outcome impacts but small use/cost impacts received only a medium overall impact.

TABLE II.2

COMBINING IMPACTS ON HOSPITAL USE/COST AND PATIENT OUTCOMES
INTO AN OVERALL IMPACT SCORE

		Impacts on Patient Outcomes		
		Small	Medium	Large
Impacts on Use/Cost	Small	Small	Medium	Medium
	Medium	Medium	Large	Large
	Large	Large	Large	Large

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[6] These distributions are based on the 67 programs that reported evidence of impacts. Impacts were expressed as a percentage of the estimate of what the outcome would have been in the absence of the program. Sixty-three programs provided evidence of impacts on hospital admissions, and 18 programs provided evidence of impacts on total medical or hospital costs (with a number providing information on both).

[7] For example: blood pressure, hemoglobin A1c levels, cholesterol levels, pulmonary capillary wedge pressure.

2. Process of Care Coordination

Study team members created an instrument to rate programs' process of care, by drawing on the extensive experience of two team members in implementing care coordination programs and advising health plans on such programs (Table II.3). The instrument identified six important domains in care coordination: (1) initial assessment and care planning, (2) evaluation and monitoring, (3) service arrangement, (4) patient education, (5) involvement of primary care physician (PCP), and (6) involvement of other health care providers. Each domain was scored from zero (lowest) to three (highest), with pluses and minuses used to refine the ratings (for example, 3+ and 2-). Scores were assigned by matching a program's descriptions of the domain to the descriptions in the instrument. The six process scores were then summed into an overall process score (+ and - modifiers were assigned values of 0.3; for example, 3- has a value of 2.7) and rounded to the nearest integer.

3. Data Collection and Scoring

Data collection and scoring were done by the project's three research analysts, who used a standardized form. At the beginning of the project, we held a one-day training session for the analysts, led by our clinician case manager team member, on rating the programs on their care coordination process. We also held several shorter sessions to train the analysts on evidence scoring. So that scoring was consistent, the training included having each analyst score a selected set of programs on both evidence and care coordination process. Then the group compared and discussed their results. The two senior researchers and case manager clinician were available at all times to discuss the analysts' questions and concerns about how particular programs should be evaluated. Program scoring was also periodically reviewed throughout the study period.

TABLE II.3

CRITERIA FOR PROCESS SCORES

Score	
Initial Assessment and Care Planning	
3	The case manager personally performs the initial assessment of the patient as soon as possible after referral. The initial assessment is extremely thorough, and all the patient's problems and potential problems are identified. The program develops an individualized plan of care, in conjunction with all other involved disciplines, tailored to eliminate the patient's problems.
2	The initial assessment and development of the care plan is not individualized and tends to be more mechanical and/or driven by rigid protocols. The case manager's initial role is limited to verifying that the patient meets entry criteria, and to authorizing entry into the program or to an appropriate level of care. The case manager may become more involved later, but only if issues arise that prevent the patient from following the protocol; the case manager then tries to resolve the problem. The program may track variations from predetermined targets or from group averages to improve the overall process and outcomes of care for all patients (variance tracking).
1	No initial assessment and no care planning are conducted.
Evaluation and Monitoring	
3	All patient contacts focus on assessing the patient's progress toward achieving the goals in the patient's individualized plan of care. The care plan is modified appropriately to respond to any changes in the patient's needs or situation. Information sources on patient progress include other members of the health care team (for example, physical therapists). The program systematically conducts variance tracking.
2	Some elements of patient contact are structured, but others are not (for example, assessment and response in the area of program focus, such as congestive heart failure, may be highly standardized and detailed, but assessment and response in other areas may be more variable). Responses to problems may be somewhat mechanical (that is, "if A then B"). The case management staff may lack knowledge, training, or protocols on resolving problems outside the program's focus.
1	The program conducts variance tracking only. There is little or no case manager involvement. The approach is population based, not individualized.
0	Contacts are unfocused and sporadic.

TABLE II.3 *(continued)*

Score	
Service Arrangement	
3	The program arranges for services as part of the overall plan of care, rather than simply in reaction to the needs of the moment. The program follows up to determine both whether the service was delivered and whether it achieved its intended goal in the plan of care. If goals are not achieved or if the patient's situation/needs change, the care plan is modified accordingly.
2	The program arranges for services in response to current patient needs but not as part of an overall plan of care. It follows up only to determine whether the service was delivered and whether the immediate problem was resolved.
1	The program identifies needed services. The patient is given information on how to obtain the services or on how to obtain authorization for them. There is no planned followup.
Patient Education	
3	The program has developed specific education programs, classes, or curricula designed for the target patient population. Case management staff receive formal training.
2	Case managers are expected to provide some education, but there are no standard guidelines on what is to be taught. There is no formal curriculum or protocol.
1	Patients are handed or mailed some educational material.
0	The program does not expect case managers to provide any patient education.
Involvement of Primary Care Physician (PCP)	
3	The case manager holds regularly scheduled discussions with the PCP to conduct initial assessment and care planning and to evaluate and monitor the patient's progress.
2	There are regularly scheduled unstructured discussions, but the PCP is not an integral part of the care coordination process.
1	The case manager talks with the PCP periodically, but only to resolve specific problems or issues (for example, if medical orders are necessary).
0	There is no communication with the PCP.

TABLE II.3 *(continued)*

Score	
Involvement of Other Health Care Providers	
3	The case manager has a broad purview. The case manager remains involved in the patient's care regardless of the care setting (that is, *across* settings). The case manager communicates directly with referral sources to obtain pertinent information. If the patient moves to another setting, the case manager remains in direct contact with providers in that setting because the patient is expected to return to the case manager's care after discharge to the home. The case manager helps the PCP keep abreast of the patient's progress and facilitates the PCP's involvement to the extent appropriate for the patient's situation and desired by the PCP and patient. The case manager's involvement also varies to the extent appropriate for the patient's situation and to the extent desired by the PCP and patient.
2	The case manager coordinates care only within the purview of a specific setting and communicates only with providers involved in the care plan for the current setting (for example, in the home setting, the case manager coordinates care only in the home, with physical therapists or aides). After the patient moves to another setting, the case manager ceases to be involved.
1	The case manager prepares the patient only to transfer to the next setting. The case manager communicates only with providers who are about to receive the patient, and only to transfer care to them.

NOTE: Scores of + and − are possible. In summing the process scores across the six domains, the + and - count as 0.3 (for example, 2+ = 2.3, and 3- = 2.7). Some areas do not have a score of zero.

We used the weighted kappa statistic to assess the inter-rater reliability of the scoring. Unlike the unweighted kappa, which treats all disagreements equally, the weighted kappa statistic incorporates ratio-scaled degrees of disagreement, thus providing "partial credit" when the scores of the two raters are close.

Different pairs of independent raters each scored 33 programs on their care coordination process and 45 programs on the quality of their impact evidence. The weighted kappa statistic for process scores was 0.45, which indicates moderate agreement between the raters. The weighted kappa statistic for quality of evidence scores was 0.64, which indicates substantial agreement.

We also used a consensus process to confirm process scores at the top end of the scale: scores from 11 to 18 (as discussed in Section E below, we used a process score of 14 or above to define "high-process" programs). First, all programs with scores in this range were scored independently by a second rater. In all but five cases, the second score did not alter the classification of a program's process score as "high" or "not high." In these five cases, however, the second score changed the program's classification (from high-process to less-than-high, or vice versa). The study team members then met to discuss in detail the process scores for these five programs and reach a final consensus on each.

Details of data collection and scoring depended somewhat on the source of the program. Determination of inclusion and scoring for programs identified in the literature was generally straightforward, since published studies provide good descriptions of the intervention, analytic methods, and results. Several telephone calls or e-mails were often required to gather all the data needed from unpublished programs. All the data collected were entered into an Access database.

C. FINDING PROGRAMS

We searched the published literature and also pursued numerous other efforts to locate unpublished programs. Limiting our study to published programs would have produced a sample heavily skewed toward academic medical centers and would have missed many successful programs developed in the private sector. It would also have missed effective programs that were more recent and had not published their results at the time of our search.

1. Literature Search

We searched three electronic databases--the Cumulative Index of Nursing and Allied Health Literature (CINAHL), HealthSTAR, and MEDLINE--to identify studies with the following subject headings: case management, comprehensive health care, disease management, patient care management, patient care planning, patient education, and self-care.[8] To widen our search, we "exploded" the search terms, which means we searched simultaneously on both narrower and broader index terms. We reviewed the reference lists of retrieved articles and surveyed new issues of relevant journals that might not yet have been indexed into the electronic literature databases.

2. Best Practices Solicitation and Search

We pursued a wide variety of avenues to publicize the study and uncover as many programs as possible. The solicitation was launched by the March 23, 1999, publication of HCFA's notice in the *Federal Register,* which called for any person or organization to contact MPR about any strong

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[8] The CINAHL database covers the literature related to nursing and allied health and is published by CINAHL Information Systems, Inc. The HealthSTAR database contains citations to published studies in health services, technology, administration, and research. The MEDLINE database provides comprehensive bibliographic coverage of the biomedical literature. Both MEDLINE and HealthSTAR are produced by the National Library of Medicine. For all three databases, professional abstraction staff assign subject headings and subheadings on the basis of an article's content.

programs in coordinated care. MPR published notices of the study in several professional journals (including *Journal of the American Medical Association, Journal of the American Geriatrics Society,* and *Annals of Internal Medicine*) and a newsletter (the Midatlantic Nonprofit Health and Housing Association Newsletter). We also sent letters to professional and trade groups (such as the Case Management Society of America, National Association for Home Care, American Diabetes Association, and American Association of Health Plans), broadcast notices on a number of relevant e-mail discussion groups, and established a "Best Practices" page on the MPR Web site (Appendix B contains a list of publicity efforts). This Web page described the study and provided a form to submit program information. HCFA also published information about the study on its Web site and established a link to the MPR "Best Practices" page. Two study team members with extensive experience in the case management field suggested a number of programs, and we polled knowledgeable colleagues for more. We also looked for programs in several recently published books that described care coordination programs (Calkins et al. 1999; Netting and Williams 1999; Christianson et al. 1998; and Forman and Kelliher 1999). We scanned trade publications and newsletters for mention of programs and monitored an active "Disease Management" e-mail discussion group. Finally, we sent a letter soliciting information on strong programs to all 353 attendees of the National Chronic Care Consortium's (NCCC's) 1999 annual conference.

We entered all program responses and leads into an Access database. Most leads contained insufficient contact information, sometimes little more than a program name, which necessitated a hunt for cities, names of program staff, addresses, and telephone numbers. We mailed out several hundred letters to programs for which we had addresses and fielded numerous telephone inquiries and e-mails.[9] We made more than 200 follow-up telephone calls to programs we had mailed letters to but from whom we had received no response. We had originally fixed June 21, 1999, as the cutoff date by which program entries had to arrive to be included in the analysis. For some programs that had sent incomplete submissions, we were able to accept necessary additional data as late as July 12.

D. ELIGIBLE AND INELIGIBLE PROGRAMS

By the end of the solicitation and search period, we had gathered enough data on 157 of the 384 program leads in our database to determine eligibility--69 were eligible and 90 were ineligible. Table II.4 lists the reasons for ineligibility. The most common reasons by far were lack of impacts on hospital cost or use outcomes and lack of impacts on any outcome measures. Despite our efforts to collect more data, we were unable to ascertain the eligibility of the remaining 236 programs and leads in the database.[10]

Table II.5 shows the basic characteristics of eligible and ineligible programs. With the exception of pharmacy benefit managers (only 2 of the 157 programs), different types of settings and sponsors were well represented among both eligible and ineligible programs. There seemed to be somewhat more commercial vendors among eligible programs than ineligible ones, and conversely, more “other” programs among the ineligible programs (such as area agencies on aging and visiting

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[9] We mailed between 249 and 602 letters. One mailing consisted of 249 programs or individuals in the Access database, and the second was to 353 NCCC attendees. There may have been some duplicate entries in the two mailing lists.

[10] The remaining entries consisted of programs that did not respond to our letters and voice mails, programs that refused to participate, and incomplete leads (for example, the contact person we had listed had left and the program was no longer operating, program name was incorrect, city was incorrect).

TABLE II.4

REASONS FOR PROGRAM INELIGIBILITY

Reason	Number
No data on impacts on any outcomes[a]	36
No data on impacts on hospital use/cost[a,b]	31
Not a true "care coordination" program[c,d]	9
Increased health care costs	8
Targeted to children or pregnant women[e]	4
Not a currently functioning program	3
No longer wished to be included in the study	1

NOTE: There were a total of 90 ineligible programs. Numbers presented here do not sum to 90, because programs could be ineligible for more than one reason.

[a] By "no data" we mean the program had no measurements on these outcome measures, in contrast to programs with data but impacts of zero.

[b] By "impacts on hospital use or cost" we mean reduction in numbers of hospital admissions, hospital costs, or total medical costs. Reductions in hospital length of stay are not sufficient for our purposes (see Section A of this chapter).

[c] Programs must serve patients with chronic, systemic illness (excludes wound care, ocular care programs) and provide care coordination (excludes suppliers of medical devices, such as urinary catheters and electronic medication reminder devices).

[d] This number includes a few nursing home only programs. Early in the study we had also excluded programs that served nursing home residents only, thus excluding a few programs. Much later in the study we did decide to include such programs, but by that point it was too late to study any of the originally excluded programs in any depth.

[e] These programs serve pediatric, obstetric, newborn, perinatal, or postpartum populations, which, at most, represent an extremely small proportion of Medicare beneficiaries and expenditures.

TABLE II.5

CHARACTERISTICS OF PROGRAMS

	Eligible Programs Number (Percent)	Ineligible Programs Number (Percent)[a]	All Programs Number (Percent)
Setting or Sponsor			
Hospital[b]	22 (33%)	17 (19%)	39 (25%)
Academic Medical Center	14 (21%)	27 (30%)	41 (26%)
Commercial Vendor	13 (19%)	7 (8%)	20 (13%)
Health Plan	14 (21%)	12 (13%)	26 (17%)
Group Practice/Multispecialty Group	1 (1%)	10 (11%)	11 (7%)
Other[c]	3 (4%)	16 (18%)	19 (12%)
Pharmaceutical Benefits Manager	0 (0%)	1 (1%)	1 (1%)
Type[d]			
Disease-Specific	37 (55%)	40 (44%)	77 (49%)
Non-Disease-Specific	30 (45%)	50 (56%)	80 (51%)
Location			
Urban	60 (90%)	82 (91%)	142 (90%)
Rural	7 (10%)	8 (9%)	15 (10%)
TOTAL	**67 (100%)**	**90 (100%)**	**157 (100%)**

NOTE: Numbers in parentheses are percentages of column totals.

[a] This number includes a few nursing home only programs. Early in the study we had also excluded programs that served nursing home residents only, thus excluding a few programs. Much later in the study we did decide to include such programs, but by that point it was too late to study any of the originally excluded programs in any depth.

[b] Includes physician-hospital organizations, integrated delivery systems, and other hospital-based entities.

[c] Includes area agencies on aging, state and county programs, home health agencies, community health centers, and other nongovernmental organizations.

[d] We categorized programs as disease-specific if they clearly sought out specific types of patient populations defined by their disease (for example, those with congestive heart failure, asthma, chronic obstructive pulmonary disease, diabetes, or heart disease). Programs that served the frail elderly or a more generic population group were categorized as non-disease-specific.

nurse associations). The preponderance of commercial vendors is consistent with their incentive to measure and show positive cost and utilization impacts. Almost two-thirds of the eligible programs were disease-specific, whereas slightly fewer than half the ineligible ones were disease-specific. Since most commercial vendor programs are disease-specific, the greater frequency of disease-specific programs among the eligibles is again consistent with their incentive to report positive impacts. Roughly 90 percent of programs (both overall and within eligibility groups) were urban. Finally, eligible programs had been in operation an average of roughly 4.5 years (median 4, 25 percent to 75 percent interquartile range from 2 to 6, not shown in table).

E. DISTRIBUTION OF SCORES AND SELECTION OF PROGRAMS FOR FURTHER STUDY

Table II.6 shows the distribution of all eligible programs by evidence quality, impact size, and process score. We first decided that "acceptable" levels of evidence were scores of 4 or greater.[11] Then, among programs with acceptable evidence, we categorized the extremes of the process score distribution as "high" (14 or greater) or "low" (10 or less). Since large and medium impacts were both sizable, we grouped them together. Thus, the category of high-process, medium- to large-impact programs has 20 programs (the 9 high-process, large-impact programs in the upper righthand corner of Table II.6, and the 11 high-process, medium-impact programs immediately below these 7). The high-process, small-impact category has two programs, in the right lower corner of the table. Finally, the low-process, medium- to large-impact category has seven programs from the upper and mid-left areas of the table (two low-process, large-impact programs, and five low-process, medium-

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[11] We chose a cutoff of Level 4 because its study designs--pre-post or comparison group studies with sample sizes between 100 and 200 and good evidence against substantial bias, or pre-post or comparison group studies and less evidence against bias but sample sizes of at least 200--constituted what we felt was the lowest acceptable quality of evidence. Level 3, the next lowest level, consisted of smaller or less rigorous studies that we did not feel constituted adequate evidence.

TABLE II.6

DISTRIBUTION OF OUTCOME, EVIDENCE, AND PROCESS SCORES FOR ELIGIBLE PROGRAMS

Overall Impact	**Evidence Score**[a]	**Process Score**[b]											**Total**
		<=8	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	
Large	**<=3**	3		2	1	2	1	3	4	1	1		18
	4	1			1	2	1[c]	2	3	2	1		13
	5	1				1	1		1				4
	6		***B***							***A***			0
Medium	**<=3**			1	1				4				6
	4	2				1				1	2	1	7
	5	1				1		2	1	2	2		9
	6	1	***B***	1						***A***			2
Small	**<=3**	2	1					1[d]					4
	4						1[e]			1			2
	5		1					1					2
	6									***C***			0
Total		**11**	**2**	**4**	**3**	**7**	**4**	**9**	**13**	**7**	**6**	**1**	
		17						**36**					**67**

NOTE: Overall impacts are defined essentially by the size of the cost impacts but give additional credit if the program also has sizable effects on patient outcomes (see Table II.2).

A = high-process, medium- to large-impact programs.
B = low-process, medium- to large-impact programs.
C = high-process, small-impact programs.

[a] Evidence scores of ≥ 4 are considered adequate.

[b] Process scores of ≥ 14 are considered high and of ≤10 are low.

[c] This program was selected for interview because of its rural location.

[d] To augment the two programs from Area C, we included this program with an evidence score of 3. This is appropriate, since evidence of weak quality tends to overstate program impacts, so better evidence would probably still have resulted in this program being classified as having small impacts.

[e] To further augment the high-process, low-impact programs, we also selected this program with a borderline process score of 13.

impact programs). These three categories are indicated in Table II.6 by shading and are labeled A, B, and C.

We felt that a sample of roughly 25 programs from these three categories would provide us with a reasonably large and representative sample of programs. We wished to select primarily from the high-process, medium- to large-impact group (Table II.6, area A), but to also include some programs from the low-process, medium to large-impact group (area B), the high-process, low-impact group (area C), and the high-process, zero-impact group (not shown in Table II.6). We selected at random 7 of the 9 high-process large-impact programs for interview, and 8 of the 11 high-process, medium-impact programs, or 15 of the 20 programs in Area A, Table II.6. We also added one more borderline high-process, large-impact program (with process score 13 and large impact) from among those not already selected, because it was rural (resulting in a total of four rural programs among those selected). In the low-process, medium- to large-impact category, we selected both of the two low-process large-impact programs to interview, and, at random, two of the five low-process medium-impact programs, or a total of four of the seven programs in area B. We selected both programs from the high-process, small-impact category (area C) to interview. To increase the number of programs from the right lower corner (high-process, small impact), we included two additional programs, one with a borderline process score of 13, and one with an evidence score of only 3. Finally, we added three high-process (scores of 14, 15, and 16) but *zero*-impact programs (not shown not in Table II.6, which lists only eligible programs).[12] We thus ended up with 27 programs to interview. The numbers of programs in each category and the number of programs selected are summarized in Table II.7.

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[12] Not surprisingly, we found few programs that measured and reported zero hospital use/cost impacts. Those we found were all research projects or demonstrations in published articles and reports.

TABLE II.7

PROCESS AND IMPACT CATEGORIES OF PROGRAMS WITH EVIDENCE SCORES OF ≥4, AND NUMBER SELECTED FOR INTERVIEW

Category	Total Number	Number Selected for Interview
High-Process, Medium- to Large-Impact[a]		
Large-impact	9	7
Medium-impact	11	8[b]
Borderline-high-process (13), large-impact	1	1[c]
Low-Process, Medium- to Large-Impact[d]		
Large-impact	2	2
Medium-impact	5	2
High-Process, Zero to Small-Impact[e]		
Small-impact	4[f]	4[g]
Zero-impact	3	3[h]

[a] Includes area A in Table II.6.

[b] One program was later not included in the final group of programs for further study because it was a group clinic intervention and not a true care coordination program.

[c] Rural program.

[d] Area B in Table II.6.

[e] Includes area C in Table II.6.

[f] One of these programs had an evidence score of only 3, while another had a process score of 13, rather than 14 or more as normally required for a "high" process rating.

[g] One of these programs was later not included in the final group of programs for further study, because it was mainly a consulting organization and not a program providing services itself.

[h] These three programs are not in Table II.6, which contains only eligible programs (that is, programs with favorable impacts).

Many of the programs selected for interview also had other positive impacts on patient outcomes or quality of care.[13] These nonhospital use/cost impacts were addressed implicitly in the categorization of impact size (Table II.2), but we list them explicitly in Table II.8.

The goals of the interviews were to understand in greater depth the details of the programs' care coordination practices and to elicit their views of what contributed to their success. The study team first developed an interview protocol that covered the same six domains as the process scoring tool but was based on several open-ended questions to permit further probing (Table II.9). The interviews were conducted by telephone by the two study team members with experience in the care coordination field. The interviewers were free to use their own judgment in pursuing topics or issues that arose during the interviews.

Interview respondents were senior program staff and included researchers (for programs run as research projects), supervisors and directors of case management services, medical or clinical directors, and (in the case of commercial vendors) senior company officials. In several cases, more than one program staff member participated in the interview. In cases where a marketing executive was being interviewed, we also asked that a clinician or clinical supervisor be present. Interviews ranged from one to two hours. The interviewing study team member completed an extensive write-up of each interview.

To arrive at the final group of programs for further study, we excluded two of the interviewed programs and added four programs that were not interviewed. One of the excluded programs did not work with individual patients and was thus not a care coordination program like the others we were studying. In this program, there was no individual assessment of patients' problems and no

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[13] As noted earlier, some hospitalizations arise from poor quality of care and are avoidable. Furthermore, hospitalizations can lead to worsened patient health and dissatisfaction. Thus, a reduction in hospitalizations could be viewed as a positive impact on quality of care as well.

TABLE II.8

IMPACTS ON PATIENT HEALTH OUTCOMES OR QUALITY OF CARE FOR PROGRAMS SELECTED FOR INTERVIEW

Program	Impacts on Patient Health Outcomes or Quality of Care
Program A	No data
Program B	No statistically significant changes in mortality and quality of life [a]
Program C	20% reduction in dietary sodium intake[b] 15% improvement in functional status [b,c] 3% improvement in weighted mean NY Heart Association Class[b] 90% of patients maintained or improved their NY Heart Association Functional Class (no comparison group)
Program D	No data
Program E	No statistically significant changes in quality of life[d]
Program F	76% improvement in ischemia [b] 270% increase in use of beta blockers[b] 275% increase in use of aspirin[b] 44% increase in patients with controlled blood pressure[b] 38% increase in patients with normal blood lipids[b] 73% reduction in incidence of myocardial infarction [b]
Program G	124% increase in performance of hemoglobin A1c testing[b] 74% increase in performance of eye exams[b] 1,150% increase in performance of foot exams[b] 62% increase in performance of cholesterol screening[b]
Program H	"Improved blood pressure control" (no data reported)[b] "Increased use of ACE inhibitors for CHF patients" (no data reported)[b] "Improved hemoglobin A1c" (no data reported)[b]
Program I	"Increased compliance of asthma medications"(no data reported)[b] "Improved blood pressure control"(no data reported)[b] "Improved quality of life" (no data reported)[b,c]
Program J	42% reduction in incidence of Pneumocystis pneumonia ($p \leq 0.05$) 100% compliance in obtaining recommended baseline data (no comparison group) 98% compliance with recommendation of receiving prophylaxis for Pneumocystis pneumonia (no comparison group)
Program K	No data
Program L	80% rate of influenza and pneumonia vaccination (no comparison group)
Program M	59% reduction in mortality ($p<0.006$)
Program N	No data
Program O	7% reduction in the number of prescription drugs per member ($p<0.10$) 88% reduction in duplication of medications of the same medication class (p=NS) Numerous other statistically nonsignificant improvements[e] 16% improvement in self-rated health status score ($p \leq 0.05$)[f]
Program P	20% improvement in hemoglobin A1c levels[b] 27% of patients identified as at high nutritional risk (no comparison group)
Program Q	No data
Program R	No statistically significant differences in functional status or depression[g]

TABLE II.8 *(continued)*

Program	Impacts on Patient Health Outcomes or Quality of Care
Program S	No data
Program T	No data
Program U	No data
Program V	No data
Program W	Mortality (p=0.02) Patient knowledge of health care benefits and services (treatment by time interaction, p=0.000) Quality of care as measured by process of care (p=0.001)
Program X	Improvement in provider patient relationship (p<0.05) [h] 5% increase in percentage without ADL limitations (site member 1)[b] 21% increase in percentage without IADL limitations (site member 2)[b]
Program Y	No statistically significant differences in quality of life or functional status[i]

NOTE: This list does not include two programs that were interviewed but later not included in the final group of programs for further study. One was a group clinic intervention and not a true care coordination program. The second was mainly a consulting organization that did not provide services itself.

We did not include the many reports of high rates of satisfaction for patients and physicians in the program without a corresponding measurement for a comparison group. Impacts are reported as the difference of the percentage of the treatment (or post-intervention) group with the outcome and the percentage of the control (or pre-intervention) group with the outcome, divided by the percentage of the control (or pre-intervention) group with the outcome.

[a] Measured by the Minnesota Living with Heart Failure questionnaire and the SF-36.

[b] No statistical tests reported.

[c] Measured by the Duke Activity Status Index (DASI).

[d] Measured by the MOS SF-36.

[e] Use of sedative-hypnotic agents, duplication of medication classes, compliance with medication orders, completion of advance directives, retinal eye exams, hemoglobin A1c tests, tetanus vaccinations, SF-12 measurements.

[f] Only in the 18 patients for whom pre- and post-surveys were available (of 140 patients with pre-surveys who started the study).

[g] Measured by the Enforced Social Dependency Scale and the Center for Epidemiologic Studies Depression Scale.

[h] Measured by such items as "getting advice about caring for yourself," "receiving explanations of procedures and tests," and "skills and competence of your primary-care provider."

[i] Measured by the SF-36, Client Satisfaction Questionnaire (CSQ-8), and the Older American Resources and Services (OARS) Functional Assessment Questionnaire.

TABLE II.9

INTERVIEW PROTOCOL

Initial Identification, Assessment, and Care Planning
How do you identify potential cases? What are the [referral] criteria, and how do you communicate them to referral sources? How else do you identify patients besides referrals: for example, through administrative data?
What happens during the assessment? Are there different levels of assessment, and who determines who gets the higher level?
Who does the assessment team talk to? Only the patient? Talk to the family? Doctor? Hospital personnel, such as discharge planners? Social worker at nursing home?
Do you prepare written plans of care? Do you have written goals for each patient and goal-directed interventions as part of the care plan?
How much time do the case managers spend on non-patient-care matters? How long does the initial assessment take?
Is the intervention telephonic only versus face-to-face? What are staffing ratios?
Patient Monitoring
What is the role of the case manager in evaluating and monitoring the care plan? How do you ensure that the care plan is being implemented? To what degree and how often do you follow up?
How active are you in the arrangement of services, both medical and social?
What are the relationships with family?
Do you follow up to find out if services were received and if they accomplished their purpose?
How do you decide when a patient no longer needs monitoring/intervention?
Do you have a process for identifying care management successes and failures? Do you feed this information back to case managers or physicians? Do you identify cases where hospital or nursing home admissions should have been preventable?
Patient Education
Describe your patient education process.
Is education tailored to the individual, that is, how do you decide whether the patient has understood the message? What are the strength and weaknesses of the patient education program? How do you decide if the staff does education well?

TABLE II.9 *(continued)*

Other Care Coordination Questions
Physician: To what degree is the PCP involved in the *planning* of the care, both initially and subsequently? How is the physician involved? How often do you talk to physicians? Get examples.
Do you do satisfaction surveys with PCPs that address case management?
What are the barriers to physician or other provider collaboration? How do you deal with physician resistance?
Other health care providers: How does the communication occur? Get examples. Is there involvement by a multidisciplinary team? [need not be in the same room together--it's more important in terms of information sharing and followup]
Pharmacy: Do you have programs to address issues of polypharmacy or other medication matters?
Family: How are they involved?
General Questions
Get data on program costs, preferably per member per month.
What key traits do you seek in hiring staff?
Are there critical changes you have made to the program the last couple of years?
What are major factors that drive the success of your program? Are there areas you would like to improve?
Where would you like to take the program over the next year or two?
Would the program work in a Medicare FFS setting? What changes in the program might be required?

coordinator of care to address those problems. Rather, the program consisted primarily of a new type of physician office visit: setting aside blocks of time in PCPs' schedules to allow structured monthly group visits of their chronically ill patients. The visits included activities usually not provided during a traditional doctor's office visit, such as socializing with other group members, health education, and reviews of patients' medical records, but the intervention did not extend beyond the group visits. As for the other excluded program, the study team members performing the interviews felt it was more of a consulting organization than a true program providing services. Finally, we added four programs with zero hospital use/cost impacts that were not interviewed: the three programs from the Medicare Case Management Demonstration, and a research program from the literature that operated from 1988 to 1990. Thus, our final group of programs for further study consisted of 29 programs.

Table II.10 lists the characteristics of the programs selected for further study. (The names of the interviewed programs are listed in Appendix C.)

F. INABILITY TO DISTINGUISH BETWEEN PROGRAMS WITH SMALL, MEDIUM, AND LARGE OVERALL IMPACTS

Although we initially tried to categorize programs by small, medium, and large overall impacts, in the end we found that program impacts were not measured precisely enough for us to do so reliably. Our original plan had been to correlate program characteristics with program impact size, to learn, for example, from the high-process, small-impact programs or the low-process, large-impact programs. Unfortunately, at the level of detail of our interview data, we could find no distinguishing characteristics between high-process programs with large and small impacts. In part, this result may be due to wide confidence intervals around the impact estimates and different degrees of bias, making categorization of impacts into these categories too imprecise. Thus, we ended up studying

TABLE II.10

CHARACTERISTICS OF PROGRAMS FOR FURTHER STUDY

Program	Disease-Specific	Process/Impacts Category[a]	Setting or Sponsor	Rural[b]
Program A	yes - CHF	high-process, large-impact	health plan	no
Program B[c]	yes - CHF	low-process, medium-impact	academic medical center	no
Program C	yes - CHF	high-process, large-impact	commercial vendor	no
Program D	yes - CHF	high-process, small-impact	hospital	no
Program E	yes - CHF	high-process, large-impact	commercial vendor	no
Program F	yes - coronary artery disease	low-process, large-impact	commercial vendor	no
Program G	yes - diabetes	high-process, medium-impact	commercial vendor	no
Program H	yes - multiple	high-process, large-impact	academic medical center	no
Program I	yes - multiple	low-process, large-impact	commercial vendor	no
Program J	yes - HIV	high-process, medium-impact	health plan	no
Program K	no	high-process, small-impact	group practice/provider organization	no
Program L	no	high-process, medium-impact	health plan	no
Program M[c]	no	low-process, medium-impact	academic medical center	no
Program N	no	high-process, medium-impact	hospital	no
Program O	no	high-process, large-impact	health plan	yes
Program P[d]	no	high-process, large-impact	hospital	yes
Program Q	no	high-process, large-impact	hospital	yes
Program R	no	high-process, large-impact	academic medical center	no
Program S	no	high-process, medium-impact	group practice/provider organization	yes
Program T	no	high-process, large-impact	hospital	no

TABLE II.10 *(continued)*

Program	**Disease-Specific**	**Process/Impacts Category**[a]	**Setting or Sponsor**	**Rural**[b]
Program U	no	high-process, medium-impact	hospital	no
Program V	no	high-process, medium-impact	hospital	no
Program W	no	zero hospital use/cost impacts	academic medical center	no
Program X	no	zero hospital use/cost impacts	academic medical center	no
Program Y	no	zero hospital use/cost impacts	academic medical center	no
Program AA	no	zero hospital use/cost impacts	academic medical center	no
Program BB	no	zero hospital use/cost impacts	hospital	no
Program CC	yes - CHF	zero hospital use/cost impacts	commercial vendor	no
Program DD	yes - CHF or COPD	zero hospital use/cost impacts	peer review organization	no

NOTE: Not listed are two interviewed programs that were later not included in the final group of programs for further study. One was a group clinic intervention and not a true care coordination program. The second was mainly a consulting organization that did not provide services itself.

Programs AA, BB, CC, and DD were not interviewed for this project. Three of these programs were from the Medicare Case Management Demonstration (Schore et al. 1997). One was from a published article.

[a] See Tables II.2 and II.3 for overall impact and process score categories.

[b] Programs based in small cities that served outlying rural areas were also classified as rural.

[c] Programs B and M were run by the same team of researchers and were covered in one interview.

[d] This program had large impacts and a borderline process score of 13. It was interviewed because it was rural.

all high-process programs with *any* impacts as a single group. We were still able to learn valuable information, however, from the few programs with low process scores but measurable impacts, as well as from our handful of programs with *zero* hospital use/cost impacts.

III. TYPES OF CARE COORDINATION PROGRAMS AND A CONCEPTUAL FRAMEWORK FOR CARE COORDINATION

We analyzed information from our detailed interviews of program staff with the goal of identifying general lessons on how best to perform chronic illness care coordination. This chapter describes how, in the course of the analysis, we categorized the 29 programs into two broad categories, non-disease-specific and disease-specific, and divided the process of care coordination into a three-step conceptual framework.

A. CASE MANAGEMENT AND DISEASE MANAGEMENT PROGRAMS

We had initially hoped to draw some overarching lessons about care coordination by considering all the programs together, but as we studied the interview data, it became obvious that programs fell into two main categories: (1) non-disease-specific case management programs ("case management programs"), and (2) disease-specific programs ("disease management programs").[1] Both types of program shared the steps of care coordination (described in Section B), but the details of how they accomplished each step were similar enough within these two categories of programs and different enough between categories, that separate analysis of the programs by category was more sensible.

Case management and disease management programs targeted different types of patients, and the characteristics and needs of the two types of patients, in turn, drove the differences between the

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[1] Unfortunately both "case management" and "disease management" are terms that have been used to describe other activities. "Case management" has sometimes been used to refer to health plans' efforts to control costs or limit services (for example, pre-authorization of services, utilization review and utilization management, or retrospective denials of coverage). "Disease management" has also been used to describe a wide variety of activities, ranging from large-scale mailings of educational materials to efforts by pharmaceutical companies to help "manage" various conditions through increased use of specific medications. In this report we use "case management" to mean those coordinated care programs in our sample that did not focus on any specific disease, and "disease management" to mean those that did.

two types of programs. The case management programs used a variety of terms to describe the patients they sought:

- “High-risk for avoidable or costly medical episodes”
- “At risk for poor discharge outcomes”
- “Frail elderly and chronically ill”
- “Multiple chronic illness or complex health care needs”
- “High risk for physiologic or psychosocial imbalance”
- “In need of assistance coping with a traumatic health event”
- “Suffering from a serious acute condition associated with major risk for deleterious long-term effects”

They all seemed to be referring, however, to the same small group of “high-risk” patients--patients who suffer from health and/or social vulnerabilities that place them at high risk for costly, adverse medical events and poor health outcomes. Not only did the programs’ patients suffer from a diverse list of problems--for example, functional dependence, cognitive impairment, depression, lack of social support, falling, unsafe housing, diabetes, poverty, heart failure--but patients could have any number or combination of these difficulties.

These characteristics of high-risk patients influenced how case management programs went about locating them and caring for them. There is no single, clear-cut, easily discerned feature with which to diagnose high-risk patients. The available identification methods include mailed questionnaires, analysis of encounter data for patterns of frequent hospitalizations or emergency room visits, and referrals from providers. Referrals, however, depended upon providers being able to recognize high-risk patients. After patients were identified, case management programs necessarily followed an individualized approach to ascertain the unique sets of problems each client faced and to tailor the care plans to overcome these problems and improve overall health and function. Since many of the problems are social or functional in nature, community resources and social support services (such as respite care, home-delivered meals, and transportation) often play an important role in planning care. Family and caregivers also play an important role in designing plans of care for people with functional or social deficits. Given the diversity and individuality of each patient's set of problems, case managers' discretion and judgment also played an important role.[2]

Disease management programs, in contrast, targeted patients on the basis of specific diagnoses. Despite the usual presence of other comorbid conditions, these patients had, by definition, one dominant health problem: the disease to be managed. Disease management programs also relied on analysis of encounter data and referrals from providers to find patients, but patients with specific diagnoses are much easier to identify from these sources than high-risk patients. Automated pharmacy data can also be used to identify patients with specific diseases. Since the disease management programs focused on common conditions, and their targets often were all members of a given population with the specific diagnosis, the number of patients could potentially be large.

By focusing on patients with specific primary diagnoses, the disease management programs dealt with a much more narrow and standardized set of problems. Patients with a specific diagnosis (for example, diabetes or heart failure) will all typically need some degree of disease-specific education in self-management, lifestyle, diet, and medication compliance, and will all need comparison of their medical treatment regimens against national, evidence-based guidelines for that

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[2] We arbitrarily use the terms "case managers" for case management program staff, "disease care managers" for disease management program staff, and "care coordinators" for staff of any type of care coordination program.

disease.[3] Disease management programs needed to be able to manage common comorbidities in their patients. They also needed to be able to recognize and handle individual medical, functional, and psychosocial problems. Nevertheless, the frequency, complexity, and scope of these comorbidities and problems is typically lower among disease management patients than among case management patients. As a result, disease management programs placed less emphasis on making care arrangements with community agencies, social support services, and family and caregivers.

Another way to summarize the difference between case management and disease management programs is to describe the former as "generalists" and the latter as "specialists." Case management programs deal with a wide range of patients and problems. Therefore, they can rely less on standardization, guidelines, and protocols than disease management programs do. Disease management programs, on the other hand, become expert in one type of patient and their problems. Standardization, guidelines, and protocols fit their work very well. Table III.1 summarizes some of these differences between case management and disease management programs.

We acknowledge that our categorization of programs as case management or disease management is somewhat arbitrary. The categorization and our observation of the two different patient populations they seem to be serving (high-risk versus main diagnosis), are based heavily on the 27 interviewed programs we selected for further study. We may not have captured other populations of chronically ill patients served by other types of programs. Furthermore, although we believe that these two *broad* types of patient populations and programs do exist, the distinction between them is not sharply defined and that there is likely some degree of overlap. Disease

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[3] This is not to say that case management programs did not also make use of national, evidence-based guidelines. Guidelines, such as those for diabetes and heart failure, are for specific diseases, however, and patients of disease management programs do all have one diagnosis. Thus, guidelines are much more important for disease management programs than for case management programs, whose patients could have numerous diagnoses.

TABLE III.1

SOME BROAD DIFFERENCES BETWEEN CASE MANAGEMENT AND DISEASE MANAGEMENT PROGRAMS

Feature	Case Management Programs	Disease Management Programs
Characteristics of Target Patient Population	High-risk for costly, adverse medical events and poor health outcomes. Medically and/or socially vulnerable.	Diagnosed with disease that program specializes in.
Methods for Identifying Patients		
Mailed Questionnaires	Mailed questionnaires asking about such items as self-perceived health, self-reported health status, prior health care use, depression	--
Analysis of Encounter or Claims Data	Searching for patients with patterns of repeated hospitalizations or emergency room visits	Searching for patients with selected ICD-9 diagnosis codes
Analysis of Pharmacy Data	--	Searching for prescriptions commonly used for the specific disease (for example, insulin or oral hypoglycemic agents for diabetes)
Provider Referrals	From providers who recognize the patient as being “high-risk” or “vulnerable.” Program may have circulated some more explicit criteria among providers of the types of patients sought.	From providers of all patients with the diagnosis
Patient Education	Tailored to individual situation. Generally no standardized curriculum or standardized educational materials. Generally no classes developed by the program itself, although may refer to classes.	Standardized curriculum. Standardized educational materials. Program may have developed its own classes.
Relative Reliance on National, Evidence-Based Disease-Specific Guidelines	Low	Extremely High
Relative Reliance on Protocols and Standardization	Low	High
Relative Importance of Arranging or Referring to Community Resources or Social Support Services	High	Low
Relative Importance of Efforts to Engage Family and Caregivers	High	Low
Relative Reliance on Case Manager or Disease Care Manager Judgment	High	Medium

NOTE: The relative importance of particular program features are subjective assessments meant to convey broad generalizations across program types. They are not meant to quantify these characteristics, nor do they refer to specific programs.

management programs may sometimes turn away some patients more appropriate for case management (when asked if any types of patients were not appropriate for their programs, a few of the disease management programs did mention patients with cognitive impairment). Conversely, case management programs may enroll some patients who more closely resemble those typically seen in disease management programs (for example, a heart failure patient with few other medical problems). Nonetheless, we find the dichotomy useful for describing alternative types of effective care coordination interventions.

B. CONCEPTUAL FRAMEWORK

After studying the detailed interview information, we found it helpful to condense the original six domains of the process scoring and the in-depth interview protocol into a simpler three-step conceptual framework.[4] We were not able to accommodate the wide variation across programs using the six original domains, and we were not able to find any other common features. For example, methods of initial assessment varied widely, from assessments at home by the care coordinator, to assessments at home by a contracted provider, to assessments in group classes, to assessments over the telephone by assistants. The amount of time patients stayed in the program ranged from 30 days, to one year, to indefinite (never discharged). Some programs used nurse practitioners as case managers; others used RNs. Care coordinator to patient caseload ratios ranged from 1:20 to 1:500 or more.

The three steps the successful care coordination programs all seemed to be accomplishing were (1) to assess patients' barriers to health and devise a plan to overcome those barriers; (2) to implement the plan and deliver the interventions; and (3) to reassess to determine whether the

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[4] The original six domains were (1) Initial Assessment and Care Planning, (2) Evaluation and Monitoring, (3) Service Arrangement, (4) Patient Education, (5) Involvement of PCP, and (6) Involvement of Other Health Care Providers.

interventions are working and, if they are not, adjust the plan by going back to step one (Figure III.1).[5] This simplified framework seemed to accommodate better the great variability we observed in the six original domains. The new Assess and Plan step encompasses the original domains of care planning, patient education, and involvement of primary care physicians (PCPs) and other providers. The Implement and Deliver step covers the domains of patient education, service arrangement, and coordination with providers. The Reassess and Adjust step is essentially the same as the original evaluation and monitoring domain, but it now also includes the domain of involvement of the PCP and other providers. This framework is consistent with other conceptual frameworks of care coordination (Wagner 1998; Pacala et al. 1995; and Case Management Society of America 1995). The circle surrounding all three steps indicates that the program itself should continually reassess and improve its performance.

We then identified within each step additional component "tasks" that seemed necessary for the entire step to succeed (Table III.2). Although we describe the steps and tasks as if they were discrete and separate, in reality, they are not: they often blend into each other or occur simultaneously. Nevertheless, we found it conceptually very useful to break down the care coordination process this way, because it helped us to organize program features and approaches by their underlying goals. We give a brief overview of the tasks within each step here; later we explain the tasks in detail and give examples.

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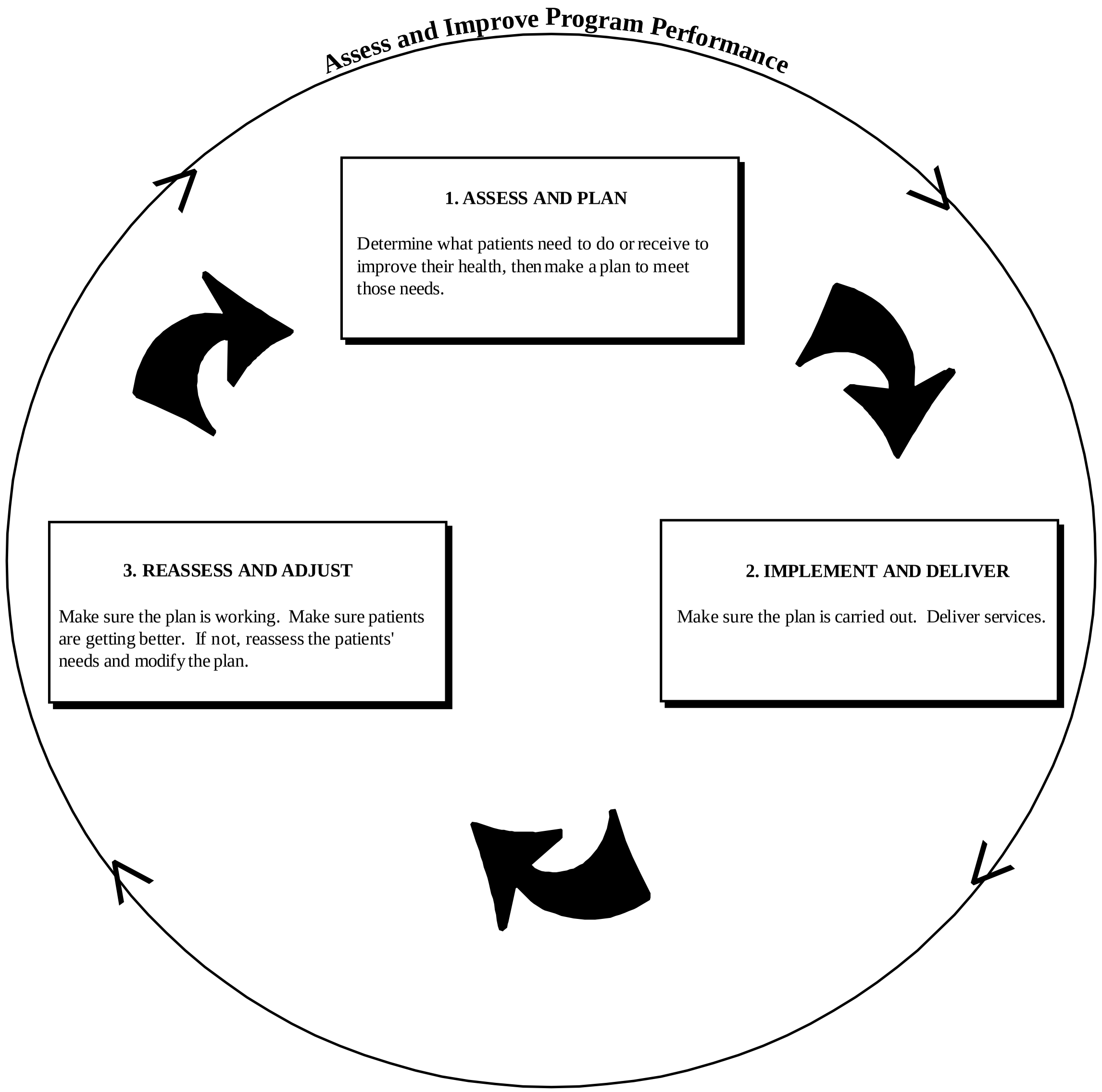
[5] For this report, we did not include Screening and Identifying Patients among the three steps (or as a separate step). Screening and Identifying Patients is an important part of care coordination (HMO Workgroup on Care Management 1996). We found, however, that how care coordination programs found and recruited patients seemed to be mainly a function of their settings (managed care organizations receiving capitation versus academic medical centers or hospitals receiving fee-for-service payment, for example). The goal of this study was to describe the services that seem to constitute effective care coordination, independent of setting or payment mechanism. Appendix D contains a description of the methods by which programs screened and identified patients.

FIGURE III.1

THREE STEPS THAT SUCCESSFUL COORDINATED CARE
PROGRAMS ACCOMPLISHED



1. ASSESS AND PLAN

Determine what patients need to do or receive to improve their health, then make a plan to meet those needs.

2. IMPLEMENT AND DELIVER

Make sure the plan is carried out. Deliver services.

3. REASSESS AND ADJUST

Make sure the plan is working. Make sure patients are getting better. If not, reassess the patients' needs and modify the plan.

NOTE: These are three main steps that the successful coordinated care programs in our study seemed to be accomplishing for each enrolled patient. Th preceding step of Identifying and Screening Patients seemed to depend heavily on programs' setting and environment, so we did not include it in th basic model. Appendix D contains a description of how programs identified and screened patients. Assess and Improve Program Performance is not among the three steps, because it occurs at the program level, not the patient level.

TABLE III.2

COMPONENT TASKS FOR THE THREE STEPS IN CARE COORDINATION

1. Assess and Plan
Uncover all important problems.
Address all important problems and goals.
Draw from a comprehensive arsenal of proven interventions.
Produce a clear, practical plan of care with specific goals.
2. Implement and Deliver
Build an ongoing relationship with PCPs, and with other providers.
Build an ongoing relationship with patients and families.
Educate patients about their disease and appropriate self-care.
Make certain that planned interventions get done.
3. Reassess and Adjust
Perform periodic reassessments.
Be accessible to patients.
Nurture the ongoing relationship with PCPs (and with other providers).
Nurture the ongoing relationship with patients and families.
Make prompt adjustments to the plan of care as needed.

In the Assess and Plan step, the first task is to *uncover all important problems*. Important problems are those barriers that keep the patient from optimum health and can lead to unplanned hospitalizations. For one patient, these barriers may include painful arthritis and slippery throw rugs that increase the risk of falling and injury. For another, they may include inadequate dosages of heart failure medications and being accustomed to overly salty foods.[6] The second task is to *address all important problems and goals* in planning care--each problem detected by screening questionnaires or home and physical assessments must be methodically addressed in the plan of care. The third task is to *draw from a comprehensive arsenal,* meaning that the care coordinator should be knowledgeable about all the appropriate, tested clinical strategies, health resources, and community services that could possibly help the patient. For example, there may be programs to help individuals pay for expensive medications, but a care coordinator who is unaware of them will be unable to help the patient who cannot afford medication. The final task is to *produce a clear plan of care with goals*. It is important for all concerned--patient, care coordinator, PCP--to have a common, agreed-upon plan with scheduled milestones. Each planned intervention should correspond to a specific goal, and the plan of care should specify when each goal is to be accomplished. Finally, the plan should contain a larger vision of the patient's ultimate objectives.

The second step, Implement and Deliver, also contains four tasks. The first two address the *relationships* of the care coordinator with *PCP and other providers,* on the one hand, and with the *patient and family,* on the other. These relationships must exist to some degree in order for the plan of care to be successful. The third task highlights the importance of *patient education,* an intervention that is part of every plan of care. This task should teach patients the knowledge

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[6] This initial assessment could and probably should also include an assessment of the patient's strengths or assets for staying as healthy as possible, but interviewed program staff spoke mostly about ways to uncover barriers and problems.

essential for self-care of their conditions, such as proper diet, medication compliance, exercise, self-monitoring skills, and coping skills. Finally, the fourth task, *making certain that planned interventions get done,* is a reminder of the persistent, methodical, and meticulous monitoring and followup that leads to successful outcomes.

The third step consists of five tasks and closes the circle of steps. The first task here, *periodic reassessments,* makes sure the patient stays on track, does not get "lost to followup," and has new problems identified early. The second task, *be accessible,* means there should be a way for patients to reach their care coordinator, whether by telephone or pager, for either routine or urgent issues. The third and fourth tasks again point to the importance of the care coordinator's *relationships* with *providers* and *patients*. The last task, *make prompt adjustments,* emphasizes the need for the care coordinator to promptly modify the plan of care in response to any new barriers or problems, or in response to patient improvement. Several interventions may need to be tried and discarded before a successful solution is discovered. Sometimes the new problems can be urgent--the patient gets a cold and heart failure suddenly worsens, or a key caregiver falls ill--and care coordinators must be prepared to intervene quickly to avert further problems.

We point out that these steps and tasks are merely issues that programs addressed; they do not say *how* programs addressed them or that they did tasks with equal intensity. Thus, in the first task of step one, *uncover all important problems,* what problems are "important" depends both on the individual patient's perspective and desires and on the problems common to the patient population being served. In one population, problems such as dementia and social isolation may be common enough that it is worthwhile to routinely screen for them; in another population, their prevalence may be low enough that routine screening is not worthwhile. In some populations, each patient may bring different problems, while in other populations, all patients may have quite similar problems. As another example, one care coordinator in a rural community may be able to accomplish the critical first task of step three (periodic reassessments) with an organized datebook and an excellent memory; another care coordinator in a central telephone center following many faraway patients may do better with a sophisticated computer tracking system.

IV. PROGRAM APPROACHES TO CARE COORDINATION

In this chapter, we use the conceptual framework developed in the preceding chapter to review the approaches taken to care coordination by several categories of programs. We first describe how successful case management and disease management programs accomplish the key steps and component tasks. Differences for programs in rural areas are then reviewed, followed by lessons learned from focusing on successful programs with relatively weak process of care (Section D) and unsuccessful programs (Section E). The final section describes programs that, although not represented in the programs we studied in depth, are targeted to important populations for policymakers: disabled persons, Medicaid beneficiaries, and chronically mentally ill persons.

A. CASE MANAGEMENT PROGRAMS

The following discussion is based on the 11 case management programs with high process scores and impacts on hospital use or costs.[1] These programs had been in operation an average of 4.2 years (median 3.5 years). A successful case management program with a low process score is discussed separately in Section D below.

1. Team and Nonteam Programs

There was a noteworthy distinction between some of the case management programs. Seven of the programs were entities separate from the practices of primary care physicians (PCPs). Thus, case managers had to work with several PCPs and practices, whichever ones the case managers' active patients used. In four of the programs, however, case managers and PCPs were actually part

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[1] One of these 11, however, is a program that was included because of favorable impacts in an earlier version, but for which a recent evaluation does not find any hospital use/cost impacts (Rucksack et al. 1998).

of the same practice or clinic staff (some of these programs had other professionals, such as social workers, as part of the staff, as well). In these programs, case managers and PCPs formed permanent teams, physically located together and sharing patients. Communication and collaboration between case managers and PCPs in these team programs was naturally quite different, and obviously much easier than in programs where case managers were external to primary care practices. For some aspects of case management, the distinction between team and nonteam programs made little difference, but for others, as we point out below, it mattered a great deal.

2. Enrolling Patients

As we mentioned in Chapter II, we did not include the important function of Identifying and Enrolling patients as a separate step in our three-step conceptual framework of the care coordination process (Assess and Plan, Implement and Deliver, and Monitor and Adjust), because we found that the way programs undertook this function seemed dictated primarily by their setting and reimbursement. Because it has a major impact on a program's cost-effectiveness, finding and recruiting patients is still an important step, however, and we briefly discuss here how the case management programs addressed it. Appendix D contains a detailed description.

a. Identifying Potential Patients

In general, many, but not all, of the programs first identified a group of potential "high-risk" patients, then performed an additional assessment to determine which patients were most likely to benefit from the case management program. The manner in which this was done, however, seemed to depend on whether programs were in organizations at financial risk for defined populations of enrollees. The five capitated programs, which were at risk for defined lists of members, tended to screen new enrollees with questionnaires in a case-finding approach. They also identified existing enrollees from hospitalizations, claims and encounter data, and provider referrals. The two hospital programs found patients from among their inpatient population, and one also relied on provider referrals. The three outpatient programs under fee-for-service (FFS) reimbursement relied primarily on patient self-referrals and provider referrals. Finally, one program in a large multispecialty group clinic with a mixture of FFS and capitated patients relied on screening questionnaires for its managed care population and on referrals for its FFS population.

b. Patient Acceptance of Case Management

An important issue for care coordination programs is the proportion of patients eligible for case management who actually consent to the program. Patient refusal was a significant problem in all three sites of the Medicare Case Management Demonstrations, with roughly 70 to 80 percent of all eligible patients declining to participate (Schore et al. 1995). Our interviews did not directly address this issue, and we have data from only the two programs that published articles in the literature. Both programs were based in hospitals, identified potential patients from among hospitalized patients, and used random-assignment designs. In the first program, only 363 of 920 eligible patients (39 percent) consented to the study, whereas in the second program, an Australian program, 762 of 906 eligible patients (84 percent) consented to the study. None of the other programs provided any data on refusal rates.

We speculate that both programs' perception of patient refusal and the actual magnitude of patient refusal depend a great deal on setting and reimbursement. Programs in a FFS setting that rely on referrals and patient self-referrals probably see only the patients who are willing entrants. They probably see fewer (and are less aware of) appropriate patients who declined their providers' referral or decided not to call the program. Providers also may refer only those patients who are likely to participate. Programs in which the case manager and the PCP are co-located also might have lower refusal rates: if a patient can be introduced to the case manager by their physician at the time of an office visit, and views the case manager as part of the physician's or clinic's staff, they may be more amenable to participation. We suspect that programs in organizations responsible for defined populations of enrollees, on the other hand, may be more aware of the "eligible but refused" problem. Refusal rates also may be higher among patients who are already in managed care and are then approached by someone wishing to further "manage" their care. On the other hand, some managed care plans may simply inform patients that they will have a case manager to assist them and their physician.

3. Step One: Assess and Plan

Once a patient is identified as appropriate for case management and agrees to participate, a case management program must assess the patient and develop a plan of care (step one). Six of the programs varied the intensity of the initial assessment by patients' risk level. They stratified patients as at high or low risk (or sometimes, high, moderate, or low risk) using either the preliminary screening data (such as from a mailed questionnaire and/or from the telephone contact to patients with "positive" questionnaires). Patients judged to be at high risk received the most thorough initial assessments, which included an in-person assessment at home or in a medical office. Lower-risk patients might receive only a telephone assessment or an invitation to attend a group meeting. One of the programs also used separate sets of case managers, one for high-risk patients, and the other for low- and moderate-risk patients. The other five programs performed the same initial assessment on all patients. If programs performed different levels of assessment, we focused on the highest level of assessment in our discussion below, since high-risk patients are in greatest jeopardy of needing expensive care and experiencing poor health outcomes.[2]

a. First Task: Uncover All Important Problems

Areas Assessed. The challenge of this first task for case management programs lay in the breadth and variety of potential problems faced by their patients. The case management programs assessed patient needs, barriers, and goals in each of the following broad areas:

- Medical (prescription medications; polypharmacy; medication compliance, knowledge of illness and self-care; height, weight, and body mass index; nutrition, receipt of routine preventive care; prior health service use; medical diagnoses; health behaviors; readiness to change health behaviors; flexibility; aerobic capacity; completion of advanced directives; physical assessment or examination; alcohol use; activity level)
- Functional (ability to perform basic or instrumental activities of daily living, walking, climbing stairs)
- Emotional (depression, anxiety, emptiness)
- Cognitive (dementia)
- Environmental (safety of home environment)
- Social (social support, social activities, caregiver burden, financial status, emergency plans, designation of health care proxy, legal issues)

The programs varied widely in the specific items assessed within each broad area. In the medical area, for example, nine programs said that they assessed self-perceived health, two said that they specifically identified polypharmacy, two formally assessed nutrition, and only one said that it assessed aerobic capacity and flexibility. All but one of the programs routinely conducted home

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[2] Some case management programs work with patients only over the telephone, without any face-to-face contact, regardless of patients' risk level. None of the programs discussed here fall into this "telephone-only" category.

assessments for patients felt to be at high risk. In three of the programs, case managers performed physical assessments as part of the initial assessment.

For the initial assessment, case managers in all the programs performed a careful nursing assessment that was individualized but organized (for example, history, physical assessment, and environmental assessment) to make sure that all the domains listed above were assessed. A few of the programs also incorporated standardized tools into the assessments. One used the Omaha Nursing Assessment Instrument, one used a locally developed assessment tool, and another included the Katz Index of Activities of Daily Living, the Geriatric Depression Scale, the Folstein Mini-Mental Status Examination, and the Medical Outcomes Study Short Form 12 (MOS SF-12). Programs that used questionnaires to perform initial population screening also had data from those instruments on the patients ultimately selected for assessment.[3] One program, a research project, had research assistants first collect standard demographic and personal data and administer a battery of standardized instruments (Short Portable Mental Status Questionnaire, Center for Epidemiologic Studies Depression Scale, Enforced Social Dependency Scale) before the geriatric nurse practitioner (NP) met the patient for the initial assessment.

Programs' estimates of the average staff time required for the entire initial assessment, including time spent on the telephone and the home visit or in-person visit but exclusive of staff travel time, varied widely. One program said that the in-person assessment took 30 minutes, but this estimate did not include the time required for the patient to fill out the 108-item questionnaire or have it administered by telephone. Another program estimated that the initial assessment took four hours,

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[3] Instruments included the Probability of Repeated Hospital Admission (PRA), the MOS SF-36, the MOS SF-12, and a 108-item instrument developed by New England Medical Center.

spread out over several contacts. Most programs said that it took them approximately an hour and a half to two hours to complete the initial assessment.

Data Sources. To identify embarrassing or unrecognized problems, programs gathered data from a number of sources other than the patient. Patients may minimize or conceal important health problems because of embarrassment (for example, cognitive deficits, incontinence, financial troubles, caregiver strain and burnout, abuse) or because of failure to recognize their significance (such as unsafe living quarters or poor nutrition). All the programs interviewed family members or caregivers (with the patient's permission) as part of the initial assessment. Five of the nonteam programs routinely gathered data from patients' PCPs and/or their office staff. In the four team programs, PCP input played a key role in the initial assessment. A program located in an area with a high concentration of specialist physicians routinely contacted all specialists involved in the patient's care. Three of the hospital-based programs also consulted hospital records and spoke to hospital staff (such as discharge planners, physical therapists, or ward nurses) during patients' hospitalizations. Case managers in one program even spoke to patients' neighbors, and in another program spoke to patients' apartment managers, if they had patients' permission and thought that it would be helpful. The following are all examples of how other sources can provide valuable information about patients: a caregiver's description of a patient's ability to dress herself, a family member's frustrated and angry tone, a physician's explanation of the interplay of a patient's diagnoses, or an office nurse's account of how the patient arrives in the office or of informal conversations with the patient while leading her into the examining room. In the following example from one of the programs, it was very important for the case manager to have collected data from the patient's physician:[4]

> The case manager felt a patient had severe problems with compliance with and understanding of his medications. She spoke to the patient's doctor and learned the doctor was worried about the patient's ability to afford his medications. The doctor would change the medication regimen every time he got new samples he could give to the patient. These frequent changes, though well-intentioned, kept the patient from learning his medications. The pharmacist identified a low-cost drug that was effective, and the doctor agreed not to make frequent changes in the medications. Prior to the case manager's intervention, the patient had been hospitalized four times in six months; since then, he has not had a hospital admission for a year.

Case Manager Qualities. Several case manager qualities that programs cited as important in general--case managers who were seasoned, had ties to the community, and had excellent interpersonal skills--also seemed particularly relevant to the first task of step one. In all programs, case managers were nurses with least a bachelor's degree in nursing, and in three programs they were advanced practice nurses (master's-prepared nurses or NPs). In addition, programs said they sought nurses with prior community or geriatric experience when making hiring decisions. An experienced case manager is more likely to detect subtle problems or deficits than even a well-trained novice. Patients will share more information with case managers with whom they have rapport, and physicians and other providers will be more cooperative with case managers whom they respect.

Influence of Patient Population. Some of the variation in programs' approaches to initial assessment may have been in response to the specific barriers to improved health that their particular patient populations faced. For example, on program admission, patients of the one program that focused explicitly on polypharmacy were taking a mean of eight medications. In contrast, patients

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[4] The vignettes in this chapter came from a variety of sources, including interviews with program staff, newspaper articles, demonstration reports, and informational literature. Names and details have been changed to protect confidentiality.

of two other programs that did not explicitly address polypharmacy were taking a mean of only five medications, and 13 percent of patients of a third program that also had no special focus on polypharmacy were taking no medications at all. As additional examples, we presume that the one program that reported routinely performing a detailed nutritional assessment with calculation of body mass index, the one program that said it routinely performed a measurement of flexibility and aerobic capacity, and the one program that cited specifically assessing patients "legal entanglements" all must have found these assessments particularly useful for their specific patient populations.

b. Second Task: Address All Important Problems and Goals in the Care Plan

This task is important, because even the most thorough and careful initial assessment will not benefit the patient if key problems are not addressed in the care plan.

Problem or Goal-Oriented Approach. Explicitly listing all the problems the case manager identifies and all the goals the patient chooses during the initial assessment increases the likelihood that nothing is omitted and that each problem and goal will be addressed by specific actions and interventions. All the programs, in fact, created such a "problem list." Whether this listing is done in a computer-based system (three programs) or a paper-based record system (the remaining programs) is less important than that it is always done. Probably the most important approach to this task is to use an organized problem- or goal-oriented approach in designing the plan of care.

Multidisciplinary Input. Another approach to this task is to incorporate input from multiple disciplines into the development of the care plan--input, for example, from the PCP, social workers, pharmacists, and physical/occupational therapists. Multidisciplinary input helps ensure not only that particular broad areas are not overlooked in care planning, but also that the data collected are interpreted properly. A pharmacist may recognize a patient symptom as a medication side effect, for example, or a social worker may raise the possibility of abuse. Only four programs seemed to approach the ideal of multidisciplinary input into every patient's care-planning process. One was the research program in an academic medical center whose patients came entirely from the inpatient population. The case managers were able to consult with everyone involved in the patient's care during the hospitalization, including PCPs, primary ward nurses, pharmacists, physical therapists, and hospital discharge planners. A second was an outpatient team program, where the team--including the geriatrician, case manager, social worker, and pharmacist--all worked at the senior health center and could hold daily meetings or "rounds" to discuss cases. In a third program, even though patients' PCPs themselves were not always interested in helping to develop care plans, the staff of the case management program itself--including case managers, a geriatrician adviser, and a pharmacist--held weekly meetings to discuss cases. Finally, in a fourth program, initial in-person assessments were conducted jointly by an NP, an RN, and a physical therapist. Another five programs usually had involvement of patients' PCPs in creating the care plan and got input from other disciplines only on an "as-needed" basis. Finally, in two programs, case managers seemed to develop care plans independently and without routine input from either patients' PCPs or other providers.

Record Systems. Another approach to this task is to use organized internal case management record systems, which should help ensure that all problems uncovered in the initial assessment are addressed. Three programs mentioned using progress notes and care plans structured by domain (for example, medical, functional, psychosocial), while a fourth used a computerized system with laptop computers.

Case Manager Experience. Again, case manager experience, cited by interview respondents as generally important to program success, is probably related to the success of this specific task as well. Experienced case managers are likely to be better than inexperienced ones at recognizing problems, and at organizing, condensing, and synthesizing all the complex data from the initial assessment into a comprehensive problem list.

c. Third Task: Draw from a Comprehensive Arsenal of Proven Interventions

This task means that, in designing the plan of care, case managers choose interventions from a menu of proven, effective interventions that is as complete and up to date as possible. A key class of intervention is the services offered by community agencies (HMO Workgroup on Care Management 1999). All the programs included such community resources as part of their arsenal of interventions, although some programs emphasized their importance more than others.[5] Community resources cited as very helpful included housing programs; home-delivered meals; income support programs; transportation services; adult protective services; adult day care; local chapters of disease-specific societies such as heart, cancer, and Alzheimer's disease associations; respite and homemaker services; community nurses; and support groups and assistance programs.

Case managers' arsenals were also varied, however. One program with no impact on hospital use/cost, which we discuss later, appears to have concentrated *only* on referrals and arrangements for community services. Other interventions might include, for example, patient education (addressed in step two), advocating for additional medical evaluation of symptoms, provision of home nursing visits (by the case manager or a home health agency) to stabilize medical problems, or helping to reduce polypharmacy (one program offered a discount to patients for using a particular pharmacy, encouraging patients to consolidate their prescriptions and making it easier to detect

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[5] Previous authors have pointed out the importance of community resource organizations for case management programs in the managed care setting (HMO Workgroup on Care Management 1999). These organizations provide key services that are not covered or paid for by the health plan.

potential drug interactions). Interventions might be highly individualized and creative, as in the following anecdote:

> The patient's wife of 50 years was his caregiver. The kitchen was her domain and her long-standing habit was to salt everything imaginable. The case manager wanted to stop this without making her feel guilty or angry. The case manager and the wife devised a plan in which the wife would lock the saltshaker in the curio cabinet as a cue to examine automatic behavior.

The menu of interventions is usually carried in each case manager's memory, although directories of local community agencies may be helpful (on paper or computerized in case managers' laptop computers). For example, if case managers are unaware of useful community programs, effective educational materials or classes, new approaches to patient education, or well-taught exercise classes, then the care plan will suffer. Besides computerization, program features helpful for this task include several mentioned earlier: multidisciplinary input, experienced case managers, and case managers with strong ties to the community.

d. Fourth Task: Production of a Clear, Practical Plan of Care with Specific Goals

A plan of care documents the agreement of the case manager, the patient, the family, and the PCP (and sometimes other providers) on the problems identified and the solutions chosen, and helps everyone stay focused and "on track." Specific goals are also necessary for measurement of progress and judgment on achievement of objectives. All the case management programs used some form of written care plan. Seven of the nonteam programs sent copies to the PCP. In two cases, it was not clear whether PCPs received copies. PCPs in the team programs naturally had access to the care plan. Seven programs reviewed the plan of care with the patient and/or family to obtain agreement and commitment. One program also gave copies to the patient and family, and one program had the patient and family initial the care plan.

4. Step Two: Implement and Deliver

After the patient is assessed and the care plan is developed, the case manager must execute the plan and deliver the chosen services and interventions. Although the first two tasks--building relationships with PCPs and building relationships with patients--are groundwork enabling the plan of care to be carried out, the crucial care coordination service that case managers provide--facilitating communication between patients and providers, and between providers themselves; and advocating for patients' treatment goals--is also embedded in these two tasks. The third and fourth tasks are additional critical services provided by case managers: patient education and overall assurance of implementation of the plan of care.

a. First Task: Build Ongoing Relationships with PCPs and with Other Providers

Developing a collaboration between case managers and PCPs is a crucial path to carrying out the plan of care. PCPs who respect and trust the case manager will be more likely to communicate important information to the case manager--such as signs and symptoms to watch for, new problems identified in the last office visit, new changes in medications, and areas that need special attention or education. These PCPs also will be receptive to important information from the case manager, such as observations on the patient and home environment, functional deficits the patient has not mentioned to the doctor, the need for equipment, and reminders of preventive care. A strong relationship with the PCP and the PCP's office staff facilitates easy access to the PCP, which may be critical if the case manager is trying to deal with an urgent problem. Also, programs that fail to engage PCPs may be limited in the degree to which they can address the medical aspects of care coordination.

The nonteam programs had a number of features that helped build relationships with PCPs. In nonteam programs, the first barriers case managers faced were making busy PCPs aware of their existence and mission and helping them to remember their role in patients' care.[6] One measure that two programs used to strengthen collaboration with PCPs was to match or assign case managers to work with a set list of PCPs. Another was to create opportunities for meetings between case managers and physicians in the course of routine care, such as having case managers regularly visit doctors' offices, accompany patients on trips to the doctor, or follow hospitalized patients. Visiting doctors' offices also allowed case managers an opportunity to build relationships with physicians' office staff. Case managers in four programs often visited doctors' offices, and they made hospital rounds in two programs. Opinions on the importance of case managers' training for fostering collaboration with PCPs varied. The three programs that used advanced practice nurses/NPs all felt that the additional training allowed case managers to discuss cases with physicians at a higher level, to use more clinical judgment, and to gain physicians' respect more easily. On the other hand, one program that earlier in its history had required nurses to have a master's degree had lowered this requirement because it found that nurses with bachelor's degrees functioned just as well. The remaining programs all used bachelor's-prepared nurses and were satisfied with their effectiveness.

Team programs had fewer overt barriers to the case manager-PCP relationship. The two team programs in which new case managers were inserted into existing practices, however, did have to contend with a different set of challenges in building case manager-PCP relationships. (The other

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[6] In all the nonteam programs, case managers worked with the patients' PCPs. There was no requirement that patients switch PCPs in order to receive case management services.

two team programs that had been established at the outset as team programs did not report any such problems.) These case managers were outsiders joining established working groups for only limited periods of time (both programs were demonstration programs). The programs cited advanced training and/or experience, as well as self-confidence, as characteristics critical for case managers to win PCP and office staff respect and trust quickly.

These two programs also had to concern themselves with defending case managers' roles. Since the primary care practices were unfamiliar with the case manager concept, the programs were concerned that NP case managers would be drafted into the daily routine of diagnosing and treating patients in office visits (thus generating FFS revenue) or that nurse case managers would be recruited to perform routine office nursing work. In practice, both programs avoided these pitfalls, perhaps because of successful education of PCPs and their office staff in the case management concept, in conjunction with the case managers' personal characteristics of experience, training, and self-confidence.

Relationships with other providers, especially with hospital staff (such as discharge planners and physical therapists), were common for programs sponsored by hospitals or physician-hospital organizations. Case managers often also had relationships with other providers, such as home health agencies, that probably facilitated case managers' getting patients the services they needed.[7]

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[7] Many care coordination experts also view the establishment of relationships between case management programs and community resource organizations as crucial (HMO Workgroup on Care Management 1999). Although interview respondents did not explicitly discuss strategies for building such relationships, we can infer that such relationships existed by the fact that case managers in several of the programs often personally set up appointments for patients with community agencies (as discussed under the last task for step two, *making certain that planned interventions get done*).

b. Second Task: Build an Ongoing Relationship with Patient and Family

A strong relationship between the case manager and the patient (and his or her family) is another critical pathway to carrying out the plan of care. A patient who trusts the case manager, who sees the case manager as an advocate, is much more likely to agree to the plan of care, follow recommendations, and contact the case manager whenever services are not delivered or symptoms appear. Patients in some of the programs described their case managers as "always there for them." The home assessments and physical assessments performed by all the programs increased personal contact and fostered the development of such a case manager-patient bond.[8]

c. Third Task: Educate Patients About Their Conditions and Self-Care

Because of its importance, we view *patient education* as a separate task, not merely another intervention. Studies repeatedly identify poor patient and family knowledge and compliance as key contributors to avoidable hospitalizations and poor outcomes in chronic illness. Programs mentioned the following areas as those that patients and families must master:

- Symptom identification and management
- Self-management (that is, patients' self-monitoring of their condition and knowing how to handle early or common problems)
- Avoidance of triggers of clinical worsening (that is, conditions or situations that exacerbate the patient's illness, such as smoking, emotional upset, or salty foods)
- Reduction of emotional and psychological distress (for both patient and caregiver)
- Dietary compliance
- Activity level appropriate for condition
- Techniques to conserve energy and avoid overexertion

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[8] Again, we are focusing only on how programs handled high-risk patients.

- Guidelines for exercise
- Medication compliance
- Compliance with recommended medical followup
- Appropriate use of emergency care
- How and when to call the PCP
- How to interact with the PCP (for example, how to ask questions or to participate more in decision making)
- Development of advanced directives and health care power of attorney

Only two of the programs had developed their own formal educational programs.[9] One program offered classes on diabetes and nutrition, and another had developed some printed materials on diabetes and congestive heart failure (CHF). About half the programs took advantage of educational resources from affiliated health plans, hospitals, or doctors' offices, handing out printed educational materials from these sources or referring patients to health education classes these sources offered. (Group classes seemed especially appropriate for lower-risk patients.) In general, however, the programs' emphasis was on intensive, highly individualized education provided by the case managers, rather than on any standardized educational curriculum for patients to follow. We conjecture that, because most patients had diverse combinations of illnesses, functional deficits, and comorbidities, programs could not apply any single curriculum to all or even most patients, but had to rely instead on case managers to gauge what each individual patient needed to learn. Case managers in most programs used written or audiotaped instructions, repetitious education, and

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[9] We view a third program that had developed an extensive array of classes (on such wide-ranging topics as heart disease, nutrition, arthritis exercises, pool exercises, tai chi chuan, herbal medicine, and humor as a coping strategy) as atypical, because it may have had incentives to develop such classes to attract Medicare enrollees.

reinforcement until the patient and the family "got it." Assessment of the patient and family's grasp of the material often involved having the patient or family demonstrate or repeat the desired behavior for the case manager. Several programs encouraged family members to become involved as much as possible in learning about the patient's problems and how to deal with them.

The provision of excellent patient education is a good example of the proactive stance implicit in case management. Teaching patients more effective self-care, improved compliance, more productive ways of interacting with physicians, and better knowledge of when to call the doctor's office or to visit the emergency room is intended to increase patient self-sufficiency and prevent problems from developing or worsening.

d. Fourth Task: Making Certain That Planned Interventions Get Done

This last task seems obvious, yet it is crucial. It involves both monitoring to make sure that interventions are done and trying to make them occur if they have not been implemented. In most of the programs, for example, the case managers (or, in some programs, case manager assistants) often made sure that patients received services by making the initial appointments for patients with community-based agencies. They also followed up with patients and families and/or the agencies to see if the services accomplished their purpose. Programs also had other safeguards or strategies in place to ensure implementation of the plan of care. In one program, regional medical directors were available to discuss lapses in implementation with the PCPs of patients for whom this occurred. Highly organized or computerized internal case management records were another defense ensuring that items were not overlooked. These records are especially valuable in making sure scheduled interventions occur as planned--for example, physician or laboratory appointments or vaccinations. Finally, some of the programs cited specific case manager characteristics--such as meticulousness, persistence, self-confidence, and creativity--as important in making sure that planned interventions are implemented. The following example shows how a case manager's persistence and self-confidence helped her build relationships with patient, family, and physician and make sure that needed changes were implemented:

> A patient with heart failure and stroke was prescribed a medication for the stroke that caused stool incontinence. The incontinence led to the patient being weakened and unable to care for herself and, the case manager felt, increased her risk of rehospitalization. However, the doctor was reluctant to modify the medication. After discussing the situation with the patient's daughters, who were caring for her, the case manager accompanied the patient to her doctor's appointment, something the case managers would routinely do for important issues involving the doctor. Although the visit did not change the doctor's mind, it did get his attention. After consulting with a pharmacist and the patient's cardiologist, the case manager then called the doctor back to discuss the input from his colleagues and persuaded him to stop the medication.

5. Step Three: Reassess and Adjust

Equally critical to good care coordination is re-evaluating patients and their care regularly to ensure the care plan is working, and making necessary changes. As with the discussions of steps one and two, we focus on how programs managed the highest-risk patients. (The lower-risk patients, as mentioned earlier, were generally handled by telephone).

a. First Task: Periodic Reassessments

All the programs addressed this task. It ensures that incipient problems are caught early, and that patients are progressing according to the plan of care (identifying problems early and "intervening proactively," as one program put it, and making sure that "patients don't fall between the cracks," in another program's words). All the programs included a comparison of patients' current status to the goals of the care plan as part of the reassessment. In all the programs, case managers' professional judgment and discretion were the most important determinant of how often patients should be monitored. Five of the programs mentioned some guidelines for case managers on frequency and mode of contact but let case managers make the final decisions. Only one guideline set a maximum limit--one home visit per week (but unlimited telephone contacts for the highest-acuity patients)--the other ones all set minimum standards. One minimum guideline was from a research study at an academic medical center; it specified case manager visits every 48 hours while the patient was hospitalized, the first home visit within 48 hours after discharge, and the second home visit 7 to 10 days after discharge. Case managers could make as many additional visits or telephone calls as they felt appropriate, however. The minimum levels set by the other three programs were quite modest: at least one telephone or in-person contact monthly in one case, and at least one telephone or in-person contact every six months in the other two cases. Again, the case managers could and generally did exceed these levels. All but one of the remaining programs left frequency and mode of contacts completely in the hands of the case managers (in one program case managers followed patients only by telephone after the first home visit for the initial assessment).

A number of programs did give estimates of how often an unstable high-risk patient in intensive case management might be seen. Such patients might have weekly or even more frequent home visits, combined with frequent, often daily telephone contacts, until stabilized.

Patients transferring from the hospital to the nursing home or home health care setting are often medically unstable and face increased barriers to health. They require more thorough reassessment, closer monitoring, and frequent modifications of the care plan. Thus, nearly all the programs paid special attention to patients being discharged from a hospital. Case managers tried to work closely with hospital discharge planners. In four of the programs, case managers also visited patients in the hospital.

It is noteworthy that case managers in *all* programs monitored patients to make sure that they were making progress and to catch problems early, even if the frequency and mode of followup was left to case managers' judgment and discretion.

b. Second Task: Be Accessible to Patients

Patients may wish to speak with their case manager for a variety of reasons, ranging from simple questions about diet or a walker, to more serious but still nonurgent issues, such as early leg swelling, to urgent, frightening symptoms, such as a sudden attack of vertigo. Easy access promotes the case manager and patient/family relationship, but it also allows the case manager to intervene early and avert an ER visit and hospitalization if, for example, the case manager can quickly assess early heart failure or benign vertigo and arrange for an urgent office visit or medication adjustment. Most of the programs provided easy patient access to case managers through telephone or pager. In the following example, a rapid response by the case manager may have prevented a hospital admission:

> Mrs. C. is a 76-year-old woman with peripheral vascular disease, diabetes, congestive heart failure, depression, diabetic retinopathy with legal blindness, arthritis, and a history of gastrointestinal bleeding. She lives with her granddaughter. Mrs. C is able to perform all activities of daily living independently, but she needs some help with money management, routine housework, laundry, and meal preparation. On a routine home visit, the case manager found Mrs. C. very weak. The physical examination revealed signs of mild congestive heart failure and some indication of possible gastrointestinal bleeding. The case manager discussed her findings with the patient's physician, and he ordered medication changes and an office visit later in the week. When she showed no improvement, she was referred to the local hospital for an outpatient blood transfusion. At her two-week follow-up visit, Mrs. C. had no signs of congestive heart failure and was taking her medication as ordered.

c. Third and Fourth Tasks: Nurturing Relationships

The next two items for step three--*nurturing the relationships with patient and family* on the one hand and *with PCPs and other providers* on the other--have a similar rationale as in step two, but now as key pathways necessary to carry out readjustments or modifications in the care plan. Features important for these two tasks--mechanisms for regular contact between case managers and patients (and families) and between case managers and PCPs and other providers, and ensuring that patients have easy access to case managers as needed--were also cited above for the first task of step three.

d. Fifth Task: Make Prompt Adjustments to the Plan of Care as Needed

The fifth and last task of step three parallels the initial planning of care task in step one and involves the same processes and program features. All relevant data gathered in the periodic reassessments should be used to modify the plan of care; plan modifications should be made by drawing on a comprehensive set of effective interventions; and the modified care plan should be clear and practical. A key element in this task is the constant comparison of the patient's current status to his or her initial status and to the goals of the plan of care. Has the cognitive deficit detected in the initial assessment progressed? Was the knee pain present before? Has the physical therapy referral improved the patient's gait? Each comparison should then prompt consideration of whether the plan of care is still useful or should be modified.

We also include here the ways in which programs handled patients who improved or stabilized. Four of the eleven successful care management programs expected case managers to discharge patients at some point. Two were research or demonstration projects with prespecified durations of followup (1 month in one case, 12 months in the other). The other two programs let the case managers make the discharge decision, with some loose criteria, such as that the patient had met goals and no longer needed close monitoring. One of these two was a team program in which the primary care doctor continued to follow the patient but the case manager ceased involvement. Five programs did not discharge patients but instead moved them to lower intensities of monitoring. The decision to move patients to these lower levels was again a matter of case manager judgment, sometimes with rough guidelines (for example, that they be medically stable, have no recent ER visits, and have no recent acute events). These included two team programs that saw themselves as patients' primary care providers and therefore followed patients indefinitely. Finally, two programs left up to case managers' discretion even whether or not to discharge patients or keep them at a low level of monitoring. These programs did say that there might be special cases that they would follow indefinitely by telephone, if warranted.

Only two programs offered estimates of the time to discharge or to move to a lower level of monitoring. One program's patients stayed in the program an average of 200 days. Another program said that patients remained in intensive case management on average four to six months before being moved to a lower level of care.

6. Summary of Program Approaches to the Tasks Constituting the Three Basic Steps

Table IV.1 presents together the approaches that interviewed programs took to accomplish the tasks in each step. These tactics fall into one of three categories: (1) program structure, (2) selection of case managers with particular characteristics, and (3) case management process. These are tactics adopted by at least one of the eleven successful case management programs to deal with their particular patient population and social and health care environment. The range and types of approaches is instructive, but it is important that no single program had all these features, nor do we imply that any one program necessarily *should* have all of them.

7. Assess and Improve Program Performance

Ideally, efforts to improve program performance would follow a continuous quality improvement (CQI) approach, in which aggregate measures of key processes or outcomes would be studied periodically to see whether they were at target levels or whether there was room for improvement. The CQI approach contrasts with the more traditional approach of retrospectively

TABLE IV.1

PROGRAM APPROACHES OR FEATURES ASSOCIATED WITH AT LEAST ONE HIGH-PROCESS CASE MANAGEMENT PROGRAM WITH FAVORABLE IMPACTS

Program Structure
CMs are assigned to particular PCPs and their office staff.
Program has multidisciplinary input into at least one phase, and preferably all phases, of the case management process.
Program has mechanisms for face-to-face contact between CMs and PCPs.
CM or program has a relationship with other providers that may also care for case managed patients (such as hospital discharge planners, physical therapists, community agencies, and social workers).
One CM is assigned to work with each patient and family.
CMs can call on senior program staff for support if they run into resistance from health care providers.
Program has highly structured, possibly computerized, internal case management record system.
Program offers a discount to encourage patients to consolidate prescriptions at a single pharmacy.
Program allows CMs some flexibility or creativity.
There are regular program staff meetings.
Program staff analyzes program performance on a regular basis.
Program promotes a culture of improving care for patients, “providing the right care at the right time” to avoid medical or social crises.
Case Manager Characteristics
CMs are RNs with community or case management experience. All have at least a bachelor’s degree in nursing. Some have advanced training (master’s, APN, NP).[a]
CMs have ties to community.
CMs have excellent interpersonal, interviewing, and teaching skills.
CMs view themselves as advocates or allies of the patient with the mission of improving care and obtaining appropriate services for the patient, and not as serving a utilization management or gatekeeper function.

TABLE IV.1 *(continued)*

CMs are thorough, careful, and "gently persistent." They are creative and have excellent problem-solving skills.
Case Management Process
CMs perform an organized initial assessment. If appropriate for the patient's situation, the following areas are assessed: - Medical - Functional - Emotional - Cognitive - Environmental - Patient goals - Social
If appropriate for the patient's situation, and with the patient's permission, the initial assessment gathers data from: - Patient, family, caregivers, friends, neighbors - PCPs/physicians - Office staff of PCPs/physicians - Review of hospital chart, if inpatient - Other health care providers (outpatient and/or inpatient)
If appropriate for the patient's situation, initial assessment includes a physical assessment.
If appropriate for the patient's situation, initial assessment includes a home assessment.
If appropriate for the patient's situation, the program instructs patient and family in the following areas: - Symptom and symptom management - Self-management (how to self-monitor) - Avoidance of triggers of clinical worsening - Reduction of emotional and psychological distress (for both patient and caregiver) - Dietary compliance - Activity level - Techniques to conserve energy and avoid overexertion - Guidelines for exercise - Medication compliance - Compliance with medical followup - Appropriate use of emergency care; plan for emergencies - How and when to call the PCP - How to interact with the PCP (for example, how to ask questions)

TABLE IV.1 *(continued)*

Education is repetitious. Patient and family must show mastery of the topic by demonstration to the CM. - CM may provide written or audiotaped instructions. - CM may refer patients and families to health education classes or programs, if appropriate.
If appropriate, CMs refer and arrange services: for example, transportation, home-delivered meals, prescription drug programs for low-income people, state programs, support groups, and local church programs.
CM strongly encourages family to attend educational sessions and become involved as much as possible.
Patients are contacted with at least a specified frequency.
The program and CMs track patients across settings.
Patients' risk stratifications are periodically reassessed.
CM is readily available to patient and family.
CMs respond quickly to changing patient circumstances.
PCPs, their office staff, and other health care providers involved in patient's care are contacted with at least a specified frequency.

NOTE: Each of these strategies was mentioned by at least one of the eleven high-process case management programs with impacts.

CM = case manager; PCP = primary care physician; RN = registered nurse; APN = advanced practice nurse; NP = nurse practitioner.

[a] We are aware of well-conceived care coordination programs that are using staff with non-nursing bachelor's degrees as care coordinators. These programs, however, did not respond to our solicitation and are not included in our study.

dissecting selected failures to figure out “what went wrong” (and often to attach blame). Only two of the programs appeared to be following a CQI approach. One of these approaches was to conduct chart reviews to gather data on indicators such as completeness of initial history and appropriateness of care plan, and to examine logs to collect process measures, such as time for a case manager to respond to a referral. The other program, following JCAHO and Medicare guidelines, was studying such topics as chart completeness and accuracy, completion of advance directives, and monitoring of patients on anticoagulant medications. All the other programs seemed to be using the conventional method of focusing on individual cases with poor outcomes. Even this more limited method exceeds what some unsuccessful programs have done to identify potential quality problems.

B. DISEASE MANAGEMENT PROGRAMS

This discussion is based on the seven disease management programs with high process scores and favorable hospital use or cost impacts. The programs had been in operation for an average of 3.3 years (median 3 years). (Three additional successful disease management programs with low-process scores are discussed separately in Section D.) Disease management programs appeared to emphasize different tasks than did the case management programs. To highlight some of the contrasts, we have organized the following discussion by the same tasks used to describe the case management programs. The reduced emphasis on certain tasks by the disease management programs seems to reflect the particular needs and characteristics of their patients.

1. Identifying Patients

Beyond looking for patients with specific diagnoses, programs applied varying exclusion criteria. One CHF program excluded all patients with any significant comorbid conditions. Another CHF program excluded those with active cancer, heart transplant, significant cognitive impairment without a caregiver, end-stage renal disease, or AIDS, as well as those without telephone access. Most of the remaining programs did not mention any additional explicit exclusion criteria.

The activities that the disease management programs undertook to identify and screen patients were generally similar to those of case management programs, with some differences due to the target patient population. Like the case management programs, the disease management programs had to identify potential patients first, then select the patients that actually had the target diagnosis. Also, as with the case management programs, the manner in which disease management programs found their patients depended on their sponsorship or settings. (A detailed description of the way in which programs found their patients can be found in Appendix D.)

The three commercial firms took a population case-finding approach, but rather than use questionnaires, they relied primarily on sophisticated computer algorithms to analyze client health plans' encounter and pharmacy data ("data mining"). These algorithms, which searched for specific ICD-9 diagnosis codes or specific prescribed medications, were all trademarked and proprietary. Data mining allowed programs to rapidly identify large numbers of the potential target population members when the programs first took on a health plan's patients. Since the algorithms are not always accurate (the software may make a patient appear "falsely positive" for diabetes, for example), the programs still had to confirm that the identified patients did indeed have the target diagnosis, generally by contacting patients' PCPs. It seemed that referrals (both referrals from providers and patient self-referrals) became a more important source of patients only after the programs had been in place for a while and had had a chance to "market" themselves and make providers and patients aware of their existence.

In contrast, three of the remaining four programs, which were not sponsored by commercial vendors, relied primarily on referrals. One program was developed by an IPA-model HMO, the second by a hospital-based integrated delivery system, and the third by an academic medical center.

Finally, the one remaining program, developed in a large, group-model HMO, focused on people who were HIV-positive, a unique condition that is determined by a single laboratory test and usually treated with a unique set of medications. Because the HMO's laboratory performed all HIV blood tests and the HMO's pharmacy dispensed all medications, the program was able to accurately identify virtually all its target population.

a. Patient Acceptance of Disease Management

The one program that discussed this issue advocated a "passive enrollment" approach, in which patients are informed that they are automatically enrolled unless they specifically refuse. The program's experience was that the passive approach achieves a 98 percent participation rate, whereas the active approach, in which patients are invited to join, achieves only a 25 percent participation rate.

b. PCP Acceptance of Disease Management

Two of the interviewed programs also mentioned encountering occasional physician resistance to their programs. One was a commercial CHF program that first telephoned PCPs to confirm the diagnosis of patients identified by the data-mining algorithm and to ask for physician agreement to enroll them. The program's telephone staff would sometimes have to contend with physicians who were angry or afraid that patients would be taken away. The callers were trained and experienced in allaying these concerns and gaining cooperation. The other program, developed in a large academic integrated-delivery system, also occasionally ran into hostile physicians who perceived the program as telling doctors how to practice or as replacing doctors with nurses. The program responded by emphasizing the centrality of PCPs in the program and making program services as useful to doctors as possible.

2. Step One: Assess and Plan

Three programs described varying the intensity of the initial assessment by patients' risk levels. They assigned patients to various risk levels using explicit criteria in computerized algorithms. Data for determining risk levels came from a variety of data sources, including encounter data, pharmacy data, and the patients themselves.

a. First Task: Uncover All Important Problems

Areas Assessed. As mentioned above, some of the differences in care coordination between disease management and case management programs seem to stem from the somewhat more limited set of problems that disease management programs typically face. Disease management programs covered the following domains in their initial assessments:

- Knowledge of the specific disease
- Poor medication compliance
- Improper diet
- Inadequate exercise
- Poor health status
- Smoking and alcohol consumption
- Inadequate stress management and coping skills
- Depression
- Lack of self-monitoring skills
- Unreadiness to make behavioral changes
- Nonconformance of medical regimen with published guidelines on quality of care

Some of the programs mentioned using standardized assessment instruments, either unmodified published ones (for example, the Duke Activities Status Index, the MOS SF-36, or a diabetes-specific instrument from University of California at Davis), or ones adapted to the program (for example, the MOS SF-12 with four additional questions, food frequency questionnaires, or depression questionnaires), or ones the program itself developed (for example, medical history questionnaires). In one of the programs, the standardized instruments were administered over the telephone by clinical assistants, then the telephone was turned over to the disease care manager to finish the assessment. None of the programs routinely explored such social or functional issues as housing, caregiver support, transportation, falling, or incontinence.

Unlike case management programs, however, all the disease management programs incorporated evidence- or consensus-based national guidelines on appropriate care into every initial assessment. For example, as part of its initial assessment, the diabetes program checked whether patients had received within the appropriate time frame the 17 preventive interventions recommended by the American Diabetes Association (such as a retinal exam within the past year). The use of guidelines tended to make disease management programs' initial assessments more structured than those of case management programs.

Data Sources. Compared to case management programs, disease management programs generally consulted fewer sources of information. Most of the programs contacted the PCP during the initial assessment mainly to confirm the diagnosis. (The exception was the program in the academic integrated-delivery system, which emphasized the primacy of the PCP's role, and in which the PCP had much greater input.) Likewise, except for the HIV program, programs did not seek family input unless the patient specifically requested it.

An exception to this narrower focus was the HIV disease-specific program that provided primary care to its patients through a holistic, case management approach. This was a team program, in which PCPs, disease care managers, social workers, nutritionists, and health educators were all located together in one clinic. Like the other disease management programs, the program relied on evidence-based guidelines in the initial assessment and planning of care. Thus, there were clear protocols on the appropriate medications and interventions for given stages of the disease, as measured by CD4+ counts and Karnofsky scores.[10] Unlike the other disease management programs, however, extensive psychosocial care was an important part of the program's services. A social worker was available for psychosocial evaluation and counseling, disability counseling, and coordination with community services, and home health agency staff were available to help maintain people at home. A psychology consultant was available for evaluation and crisis counseling. The program actively sought involvement of family, partners, and caregivers.

HIV may be one of the few disease states that lends itself to such a holistic, primary care team approach for patients with a specific diagnosis.[11] HIV is usually the defining condition in the lives of HIV-positive people; they typically have few other comorbidities that are unrelated to HIV or that AIDS specialists are unprepared to handle.[12] In contrast, a team clinic approach focused only on diabetes, for example, would probably not work as well, as diabetics generally have other comorbid conditions (such as coronary artery disease, peripheral vascular disease, or renal insufficiency), for which diabetologists often refer patients to other specialists.

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[10] CD4+ cell count is a laboratory test, and Karnofsky score is a measure of functional status. The article describing the program was published before quantification of viral load, a more recent laboratory test, had become widely available.

[11] As discussed at the end of this chapter, severe physical disability and severe mental illness may be two others.

[12] This particular program served an employed, relatively well-to-do population, whose primary risk factor for HIV was homosexuality. In other settings, HIV patients are often poor, suffering from substance abuse and mental illness, and leading chaotic lives. In order to meet their clients' needs, programs serving such a population would likely also have to adopt a holistic approach, although for somewhat different reasons.

There was wide variation in *how* initial assessments were done. Initial assessments in the CHF program of a community hospital/integrated-delivery system were done through home visits. In contrast, initial assessments in two other CHF programs (one a large, national vendor, the other a statewide program of a health plan) were conducted entirely by telephone by disease care managers in telephone centers that could be hundreds of miles away from the patient. Both of these programs contracted with local home health agencies, however, to conduct home visits and physical assessments. The home visits included surveying medicine cabinets for prescribed medications and checking kitchen cabinets to gauge salt intake. Yet a third method was an initial group meeting of 10 to 12 patients for assessment and instruction in the program. Finally, the HIV team program conducted its initial assessments in its own medical clinic.

Disease Care Manager Qualifications. Although disease care managers' training and qualifications are probably relevant to every task and every step, we mention them here because they certainly influence disease care managers' ability to uncover all important problems. As in the case management programs, disease management programs employed care managers with at least a bachelor's degree in nursing. Several also specifically mentioned looking for nurses with good clinical skills or a disease-specific background (such as cardiology or diabetes). One program required nurses to have master's degrees.

b. Second Task: Address All Important Problems and Goals

The seven disease management programs all used a problem-oriented approach to make sure that all problems were addressed. The range of possible goals, however, seemed narrower than in case management programs. Goals were all related to the specific disease. Some of the programs even presented patients and disease care managers with a standard list of goals from which they chose the patient's own set of goals. In these cases, there did not appear to be a good system for eliciting and incorporating any individual or distinctive goals the patient might have.

With a few exceptions, programs did not make much use of multidisciplinary input. In six of the programs, PCPs had little input into the development of the care plan. The PCP's role seemed to be mainly to confirm patients' diagnoses and approve orders. The academic integrated delivery system program that stressed the PCP's role did communicate more with the PCP, however. Besides the HIV team program, none of the other programs really had any input from other disciplines, such as pharmacists or social workers. In the HIV program, patients often saw team members from different disciplines--for example, the nutritionist, psychiatric social worker, or pharmacist.

c. Third Task: Draw from a Comprehensive Arsenal of Proven Interventions

This task was also somewhat less relevant for the disease management programs than for the case management programs. For case management programs, the case managers had to be able to enlist a wide array of community services and resources to help meet patients' needs. In contrast, arrangement of such services played little part in the efforts of disease management programs (again with the exception of the HIV program). If needs for supportive services did arise, the programs generally referred them to the health plans' case management staff. The focus seemed to be on patient education and ensuring that care conformed to national guidelines, and less on the creative, individualized approaches of case managers.

d. Fourth Task: Production of a Clear, Practical Plan of Care with Specific Goals

The seven programs all completed step one with some form of written plan or schedule. In three of the programs, the same software system performed all of the following functions: presenting the standard list of goals from which to choose, tying the selected goals to standardized schedules, tracking patients' progress, and reminding disease care managers of due dates of interventions. (Two of the programs did not call or view their final plan a "plan of care," saying instead that they used "care maps" or "clinical pathways.") The other four programs also used computerized templates to produce written plans of care, although these plans were not necessarily tied to a tracking and scheduling system.

3. Step Two: Implement and Deliver

The execution of the care plan and delivery of services by disease management programs reflected the somewhat narrower range of interventions compared to case management programs. Most of the disease management programs' efforts in this step centered on delivering patient education and making sure that care conformed to national guidelines.

a. First Task: Build Ongoing Relationships with PCPs

Although one program cited a trusting *relationship with the PCP* as critical, the other programs did not seem to emphasize this task as much, especially compared to the case management programs.[13] We can only speculate as to why this might be so. One possible explanation is that managed care organizations (MCOs) may be more willing to pressure PCPs to comply with disease management efforts than they are with case management efforts, and PCP cooperation thus becomes less a product of good care coordinator-PCP working relationships than of MCO leverage (such as through contractual arrangements, financial incentives, or threats of exclusion). Unlike case management programs, which tend to be "home grown" within managed care organizations (Pacala et al. 1995), disease management programs tend to be developed by external commercial vendors that then contract with big managed care organizations. MCOs pay disease management vendors

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[13] Disease care managers worked with the patients' PCPs. There was no requirement that patients switch PCPs or see any particular designated specialist physicians (beyond the normal preexisting referral patterns or networks within the health plan).

large sums of money for their services, and vendors may, in turn, promise substantial savings to the MCOs (Lewis 1999). Under these conditions, MCOs, or the disease management companies, or both, may be more willing to exert pressure on PCPs. One program did, in fact, cite MCOs' ability to get them access to PCPs and to influence PCP behavior as contributing to the program's success. Compared to case management programs, some of the programs were more intrusive on physicians--for example, auditing physicians' office charts for compliance with guidelines (such as determining the percentage of diabetic patients receiving a hemoglobin A1c laboratory test).

Other possible explanations center either on the nature of care coordinators' recommendations to PCPs or on the needs of case management patients versus disease management patients. Perhaps, compared to case managers' requests, disease care managers' recommendations to PCPs are more often backed by evidence and guidelines, less disputable, and therefore less dependent on PCP goodwill for implementation. Perhaps, compared to case management patients, disease management patients manifest fewer needs or problems that require care coordinator-PCP interaction, such as the need for a walker, commode, home oxygen, or hospital bed, or problems such as falling or incontinence.

Some of the large, national programs did, however, mention occasional physician resistance. They used such strategies as introducing the program at hospital conferences and enlisting a respected local clinician leader to win acceptance for the program among peers. Others used special liaison staff members to work exclusively with physicians. These staff members dealt mostly with large physician practices or practices with large numbers of target patients. They "pitched" the program to physicians, provided education to physicians and office staff, and helped practices make systematic care improvements for the disease.

b. Second Task: Patient-Disease Care Manager Relationship

Not surprisingly, most of the disease management programs, like case management programs, felt that the *patient-care manager relationship* was critical, since it is through this relationship that patients are motivated to make necessary changes in their lives. Respondents, even those from predominantly telephonic programs, described nurse-patient bonding, human contact, and a caring attitude as crucial to their success. Two of the programs were proud of their low dropout rate. Care managers used words like “coach,” “cheerleader,” and “personal trainer” to describe their roles. Care managers in the telephonic programs made efforts to chat with patients about work and family during telephone contacts, and they sent photos and brief biographies of themselves to personalize the relationship. In one program, care managers sent congratulatory cards to patients for achieving personal goals, such as weight loss or improved exercise capacity. Programs cited the ability to relate sympathetically and optimistically to patients and to motivate them over the telephone as important qualities for care managers. The programs were somewhat less concerned about family involvement. Most of them said that they involved family only to the extent that the patient desired.

c. Third Task: Educate Patients About Their Disease and Self-Care

All the disease management programs placed great importance on this task and devoted significant thought and resources to it. In hiring, two programs specifically looked for care managers with substantial training or experience in patient education. Programs focused their patient education on knowledge and lasting behavioral changes. Like case management programs, the interest in education stemmed from a belief in prevention and being proactive. Unlike the case management programs, however, most disease management programs had a standardized content based in part on national guidelines but tried to customize the education for patients by using a wide variety of settings and formats. Thus, several programs delivered one-on-one education (at home or the PCP's office) by telephone and in group classes. One of the telephonic programs even felt that teaching by telephone was more effective than teaching in person, because older patients concentrate harder on telephone calls and are less easily distracted. Programs mentioned trying to use each patient contact as an educational opportunity and dividing the amount of information into digestible pieces. One of the programs based its educational programs on sound research from educational psychology on how adults learn and prepare to change their behavior. Programs also used printed materials or workbooks, some of them personalized. For example, two programs provided patients with regular graphical reports of their personal progress in such goals as decreasing salt intake or improving blood sugar control. Besides print materials, one program had a telephonic "AudioHealth" system that patients could dial for education. This system tracked the programs patients had listened to. Another program was developing Internet-based patient education programs.

Many programs were motivated to measure how well patients were actually learning the material. Some had the care manager informally assess whether the patient had grasped the material by having the patient display appropriate actions or knowledge ("tell me what you would do if you developed..."). Other evaluation strategies used included formal before-and-after testing of patients' knowledge, patients' evaluations of the quality of their instruction, and peer observation of disease care managers' teaching skills. One program had special education quality-improvement nurses listen in on care manager telephone calls with patients.

The following is an example of how successful patient education can improve patients' symptoms and keep them out of the hospital:

> Eighty-year-old Hector C. had Class IV congestive heart failure (CHF) and had recently been hospitalized several times for pneumonia and heart failure. He was chronically short of breath and needed assistance just to get out of bed. Shortly after enrolling in the heart program, Hector was assessed by his disease care manager, Rhonda E., a former cardiac

> and intensive care nurse. She learned that besides his CHF, Hector also had chronic obstructive pulmonary disease. He was so short of breath that he could not walk up the 13 steps from his basement without resting, and he was retaining so much fluid that it was literally "weeping" through his skin. She found that Hector was consuming far too much sodium and had no understanding of daily dietary requirements.
>
> Rhonda began to educate Hector. She taught him to plan and prepare a restricted, healthier diet; to recognize and report his symptoms; and to take his medications properly and consistently. As Hector's condition improved, Rhonda worked closely with his physician to optimize his medications.
>
> Hector is currently completely compliant with the medication regimen recommended and adjusted by his physician and Rhonda. He is no longer bothered by frequent bouts of pneumonia, and the shortness of breath that made a trip down to his basement such a hardship has diminished. He regularly accompanies his wife on her shopping trips and is no longer left feeling "drained and exhausted" afterward. Moreover, Hector has cut his sodium intake by half and remains in compliance with his dietary regimen. As a result, his swelling has completely resolved, he has no acute symptoms of heart failure, and he is feeling much better.

d. Fourth Task: Making Certain That Planned Interventions Get Done

To accomplish this task, programs gathered data from a variety of sources, used reminder systems, and relied on a combination of telephone calls, feedback, and enforcement. In contrast to the case management programs, many of the programs used computerized care-planning software that reminded care managers when certain interventions were due. One system, for example, classified interventions as "due today," "overdue," and "already done." Incomplete items were reclassified as "due today," "due the following day," or "overdue." Care managers talked to patients and PCPs to keep track of whether interventions were completed. Some of the larger programs also had access to the encounter data of their client health plans to learn whether laboratory tests had been done and prescriptions dispensed. Programs used reminder telephone calls to patients and physicians to deal with unfinished interventions for individual patients. They dealt with aggregate performance by providing feedback to PCPs on, for example, the percentage of hemoglobin A1c laboratory tests completed compared to other practices. In a few programs, health plan medical directors or other clinical leaders could speak to noncompliant physicians. In general, these efforts were more systematic and automated than those in case management programs.

4. Step Three: Reassess and Adjust

a. First Task: Periodic Reassessments

For this first task, programs made heavy use of computerized systems and technology, something few of the case management programs did. Computerized systems lend themselves well to this task: implementing protocols that recommend when patients should next be contacted based on current data, reminding care coordinators when contacts are due or overdue, and outlining the recommended content of each contact. One heart failure program has an innovative computerized system that calls patients regularly to ask a series of questions (for example, "Are you taking your medication as ordered?" "Have you had any swelling?" "Do you have any shortness of breath?"). Patients respond by pressing buttons on their telephone, and the program has branching logic. Patients can transfer themselves to a care management nurse at any time, and any worrisome response also transfers the patient to the nurse. Another heart failure program asked patients to contact the program daily, either by an automated Interactive Voice Response (IVR) system or through a Web site. In addition to answering questions, patients enter their pulse, weight, and blood pressure. If the patient fails to make daily contact or submits measurements that fall out of preestablished bounds (called an "exception report"), the nurse notifies the PCP immediately and calls the patient back to investigate further. The following incident illustrates several of the program elements described above:

> Seventy-nine-year-old Fred S. had had repeated hospitalizations for heart failure and diabetes. Now, every morning, he measures and records his weight, blood pressure, pulse, and blood sugar. Then he calls the diabetes program number. Cued by a series of prompts, Fred uses the telephone keypad to punch in his weight, blood pressure, blood sugar, and pulse and to answer questions on how he's feeling. A computer on the other end analyzes

> the data. If any readings are out of bounds, Fred's nurse from the diabetes program, Cathy J., calls him.
>
> When Fred entered the diabetes program, his doctor told them what his target levels for weight, blood pressure, and blood sugar should be. Fred learned how to use a touch-tone telephone as a data-entry tool, and he was assigned to Cathy. "If my readings aren't right or I don't call, Cathy calls and asks me to do them over, or sometimes she calls my doctor," Fred said. "I've had to adjust my diet because of my heart condition. I asked Cathy if she had any low-salt recipes for Louisiana cooking. She sent over some of her home recipes." Since he started the program, Fred has lost 40 pounds and has finally managed to lower his blood sugar.

As with the case management programs, the periodic reassessment and monitoring of patients serve a preventive purpose of catching and resolving problems early, and *all* programs performed this task.

b. Second Task: Be Accessible to Patients

All the programs provided patients with access to a disease care manager or call center through telephone or beeper. One heart failure program even had in place a rapid response system to avert hospitalization. A care manager who identified a rapidly worsening patient, either through a scheduled telephone call or by the patient calling in, could quickly send a home health nurse out to the patient's home. Then, if appropriate, and under the PCP's preestablished orders or telephone supervision, the nurse could administer intravenous diuretics, thereby averting an ER visit and probable hospitalization.

c. Third Task: Nurture Relationship with PCP

As mentioned earlier, most of the disease management programs seemed to place less emphasis on developing collaborative relationships with PCPs. Several programs did, however, provide PCPs with regular faxed or mailed updates on their patients' progress, with minimum frequencies ranging from every 30 days to every six months. Disease care managers also called PCPs as needed on specific issues or for urgent developments. Disease care managers in the program in which patients made daily reports on their vital signs called PCPs' offices to make "exception reports."

d. Fourth Task: Nurture Relationship with Patient

This task involves the ongoing relationship established earlier between the disease care manager and the patient. Disease care managers continued to nurture the relationship with the strategies already described under the task "Build an Ongoing Relationship with the Patient" in step two (Section B.4.b). They provided support and encouragement through frequent personalized contacts either by telephone or in person.

e. Fifth Task: Make Prompt Readjustments to the Plan of Care As Needed

All seven programs had mechanisms to adjust the plan of care to changes and developments in patients' status. An extreme example is the rapid-response system described above. More generally, all the programs restratified patients' risk level with each contact. One program performed a restratification with the receipt of each new piece of information (such as laboratory data, hospitalization, diagnosis, or prescription). As with the initial risk stratification in step one, restratification was based either on disease care managers' implicit judgment or on explicit algorithms and guidelines. The risk levels established a minimum frequency of followup, which disease care managers could exceed for patients they judged to need more frequent contacts.

Programs varied in how they handled patients who improved or stabilized. Most of the programs, in fact, did not discharge patients but moved stable patients to lower levels of monitoring. Their argument was that chronic illnesses are lifelong, that even stable but chronically ill patients need occasional monitoring or support, and that chronically ill patients are always at risk of falling into bad habits or suffering an exacerbation of their illness. One CHF program always discharged patients within three to six months. Another two programs discharged their patients whenever the disease care managers felt that the "time was right"--that is, when the patient demonstrated good self-care skills and had not had an ER visit or hospitalization for some period of time.

5. Assess and Improve Program Performance

Most of the disease management programs took a somewhat more systematic approach than did the case management programs. Four of the seven programs produced periodic reports of events such as hospital admissions, ranging from monthly to quarterly. These reports were used for discussion by program staff at meetings, for review by quality assurance committees, and for feedback to care coordinators. Three programs also provided this information to the PCPs. One program that did not produce formal reports of hospitalizations did review samples of admissions to make sure that program procedures were followed in each case and that nothing else should have been done. Programs also studied a variety of other performance indicators: patients with high expenses, care manager and patient compliance with the programs' guidelines (for example, eye examinations for diabetics), patient dropout rates, patient satisfaction, PCP compliance with recommendations for medication adjustments, and number of "exception reports" (for the program described earlier). One program held a monthly "tough nut" conference for care coordinators to discuss difficult cases. In addition, some programs continuously evaluated the quality of their education, as outlined above. Not surprisingly, use of electronic medical records and standard protocols provided a better framework for systematic quality assurance efforts for disease management programs than for case management programs.

6. Summary of Approaches to Basic Steps and Component Tasks

Table IV.2 lists the approaches that these successful disease management programs took to accomplish the tasks in each step, categorized by program structure, disease manager characteristics, and disease management process. As in our summary of tactics taken by case management

TABLE IV.2

PROGRAM APPROACHES OR FEATURES ASSOCIATED WITH AT LEAST ONE HIGH-PROCESS DISEASE MANAGEMENT PROGRAM WITH ANY IMPACTS

Program Structure
If a large, national program, then personnel include liaison staff to work with physician practices, promote program, and educate doctors.
Program has the option of providing continuing medical education to participating physicians through case conferences or “case of the month” mailings.
Program can offer a variety of educational programs and materials: - Care manager or other educator one-on-one with patient, in person, or by telephone; in PCP’s office, at home, or other setting; possibly Internet or Web-based learning, possibly interactive prerecorded telephone learning - Group classes - Amount taught tailored to patient’s readiness to learn at each contact - Large national programs have capability of contracting and training local patient education staff - Printed workbooks or pamphlets, newsletters, Web page - Periodic feedback to patients, for example, graph based on food frequency questionnaire showing progressive reduction in sodium intake, personalized reports on other parameters (for example, weight, blood pressure, lipids, hemoglobin A1c)
Program is regionalized, with disease care managers in regional telephone centers and contracted local home health agencies providing home and physical assessments.
Program promotes a culture of prevention, of “we care!”
One disease care manager is assigned to work with each patient.
Program has: - Regular review of cases with untoward outcomes: hospitalization or high costs - Regular reports on program performance (tracking such things as clinical process measures, patient satisfaction, patient dropout, health services utilization) to care managers and PCPs - Regular quality assurance meetings or committees - Staff devoted to process improvement

TABLE IV.2 *(continued)*

Care Manager Characteristics
Nurses with experience in disease area (for example, cardiology) and strong clinical skills. All have at least a bachelor’s degree in nursing.
Experience or certification in patient education
Autonomy, self-confidence, optimistic attitude; thorough and detail-oriented
Strong interpersonal and telephone skills
Comfortable with motivator, coach, or cheerleader role for patients
Disease Management Process
Initial Assessment: - Is based on national guidelines (for example, AHCPR and AHA CHF guidelines, ADA and AADE diabetes guidelines) - Reviews history of current illness and symptoms - Records all medications - Records medical history - Assesses psychosocial situation (for example, family support, social support) - Screens for depression - Assesses functional status - Reviews smoking, alcohol use - Assesses exercise level - Assesses diet (preferably by food questionnaire or even inspection of kitchen) - Includes option of a physical assessment - Includes option of home visit - Incorporates relevant laboratory testing (for example, hemoglobin A1c for diabetes, lipids for coronary disease, ambulatory ischemia monitoring) - Assesses basic knowledge of disease process - Assesses readiness to change (for example, Prochaska’s Readiness to Change model) or likelihood of change - Produces a written plan of care with goals, ideally as part of the disease management program’s electronic medical record system
Program communicates with or updates PCP on a regularly scheduled basis (can be by mail, fax, e-mail, telephone).
If a large, national program, then program has the capability of performing pre-implementation publicity to patients and PCPs to gain acceptance.
Care manager reassesses patient knowledge and performs patient education at every patient contact.

TABLE IV.2 *(continued)*

Program may have preestablished program or calendar milestones of where patient's knowledge and skills should be at certain points in the disease management program (second week, third month) or in the year (for example, New Year's). These milestones may be "scripted" for the care manager ("It's New Year's. Have you thought about...").
Patient education program teaches or reinforces: - Disease process, identification of early warning signs and symptoms - When and how to call for medical help, emergency plan - Function and side effects of patient's medications, medication compliance - Proper diet, dietary compliance - Proper exercise and limitations, exercise compliance - Stress management and coping skills, community support groups and other resources - Smoking cessation - When and how to follow up with primary care and other physicians - Self-monitoring--for example, pulse, weight, blood sugar
Patient education assesses patient learning, either informally by asking patient to repeat or demonstrate knowledge, or formally through post-testing of patients and evaluation of care manager or patient educator's educational skill (patient questionnaire, peer observation).
Disease care managers coordinate services and durable medical equipment requests with health plan case management and benefits departments.
Program makes regularly scheduled contacts with patient, either through "outbound" calls by care manager or through "inbound" calls by the patient (for example, Interactive Voice Response, Web page submission). Computerized record systems may help ensure that contacts are not missed, especially for large programs.
Program has a way for patients to call in easily and a way to respond rapidly for quickly changing patient status.
Program has a means of flagging what interventions from the care plan are due or overdue, finding out if they have been completed, and, if not, making sure they occur. Patients and PCPs are the main sources of information on whether indicated tests or appointments have occurred, but some large programs also have access to claims data. Again, computerized record systems to track interventions may help in large programs. Interventions are based on national guidelines for care.
Patient's risk stratifications are periodically reassessed.

PCP = primary care physician; AHCPR = Agency for Health Care Policy and Research, recently renamed Agency for Health Care Research and Quality (AHRQ); AMA = American Heart Association; ADA = American Diabetes Association; AADE = American Association for Diabetes Educators; CHF = congestive heart failure.

programs, we point out that these tactics reflect programs' responses to particular patient populations and situations. No single program possessed all these features, nor does one necessarily have to.

C. RURAL PROGRAMS

Four successful programs functioned either partially or completely in rural settings.[14] One program was a multidisciplinary team, and the rest were case management programs. The absence of rural disease management programs probably reflects the low penetration of managed care plans into rural areas.

In general, these four programs shared the same characteristics as those of other successful case management programs. They used similar staff and addressed the same steps and tasks.

These rural programs had two noteworthy characteristics. One was that case managers having close ties to the community seemed especially important. In one program, this was cited as an aid in understanding the history of the community and in gaining patients' trust. In another program, community ties helped case managers find the creative solution of having local police and fire officials periodically check in on patients. The second characteristic was constraints imposed by travel and transportation over long distances. Case managers could not handle as many patients because of the long driving distances, and in order to get patients into the city for specialty care, case managers had to orchestrate and closely monitor complicated transportation arrangements. Case managers also felt that the infrequent contact with the outlying physicians made it difficult to develop collaborative relations with them. One rural program spoke of trying to use the telephone more to compensate for the difficulty of making home visits. Another program was experimenting with "telenursing" or using a video link to patients' homes to monitor them.

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[14] Two programs were based in large towns or small cities but served patients in outlying rural areas.

D. SUCCESSFUL PROGRAMS WITH LOW PROCESS SCORES

Finally, we examined the four programs with *low* process scores and high or medium impacts in search of clues as to whether some program elements are optional and others crucial.[15] Information on whether certain program elements are dispensable has important implications for the cost-effectiveness of care coordination programs. Three of the programs were disease management programs (one CHF, one coronary artery disease, and one covering multiple diseases); the fourth was a case management program. The CHF disease management program and the case management program were both conceived by the same investigators at an academic medical center, were both called a "home-based intervention" (HBI), and were essentially identical, differing only in the CHF program's restriction to heart failure patients.

In comparison to some of the other case management programs, the intervention in the HBI case management program, which was a randomized trial that enrolled hospitalized patients, was limited in both scope and duration. The entire intervention consisted of in-hospital counseling by the study nurse and pharmacist on medication compliance and early recognition and reporting of clinical deterioration; and then, for high-risk patients,[16] a single home visit by the nurse and pharmacist focused on medication compliance and a physical and psychosocial assessment. In the home visit, the pharmacist assessed the patient's medication compliance through pill counts and knowledge through a questionnaire. If patients had low compliance or knowledge, the pharmacist performed

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[15] Recall that programs were considered to have at least "medium" impacts if they reduced hospital admissions by at least 34 percent or total cost by at least 26 percent. Programs with smaller effects on hospital use/cost but with added effects on measures of patient well-being exceeding 10 percent were also considered to have "medium" impacts (see Chapter II for details).

[16] Patients in this study were classified as high risk for rehospitalization by the presence of two or more of the following risk factors: age 60 years or older, prescription of two or more medications, unplanned admission within the preceding six months, and living alone or possessing limited English language skills. Patients with zero or one risk factor were classified as low risk and received the in-hospital visit but not the home visit.

the following five steps: (1) additional counseling, (2) provision of a compliance device and/or daily medication schedule, (3) arrangement for increased monitoring by caregivers, (4) provision of a medication information/reminder card, and (5) referral to a community pharmacist for ongoing monitoring (for example, review of compliance and problems at each refill). The nurse then performed a physical assessment and reviewed pertinent symptoms since discharge (for example, exercise intolerance in patients with CHF). The nurse immediately called the patient's PCP for further care if there were any early signs of clinical worsening. Otherwise, the nurse then did a psychosocial assessment and referred patients with any additional needs to community services. Finally, the nurses contacted the patients' PCPs, informed them of the results of the home assessment, and recommended any additional actions or followup.

Although this program apparently did not include many elements we saw in the other case management programs--detailed assessments of patient functioning, cognitive status, emotional status, financial status, environmental safety, nutritional status; arrangements for homemaker services, medical transportation, in-home meal delivery--it still may have accomplished the three steps *for the patient population served*. The article describes only patients' mean age, primary diagnoses, and comorbidities and has no information on functional deficits or availability of caregivers. Although patients were indeed elderly and had serious chronic illnesses, the mean Charlson Comorbidity Index (± standard deviation) was only 1.3 ± 0.7.[17] If the patients this program serves do not have a high prevalence of dementia, frailty, or dangerous living conditions, then intensive counseling on medications and when to call the doctor for help, as well as a brief

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[17] The Charlson Comorbidity Index is a simple weighted sum of comorbid diagnoses originally developed to predict mortality. Zero represents no comorbid conditions, whereas 5 is considered a relatively high burden of comorbidity.

psychosocial assessment, may very well identify and address "all important problems"; this process would accomplish steps one and two.

The three disease management programs with low-process scores contrasted in different ways with the others we studied. As mentioned earlier, the CHF HBI program was essentially the same HBI case management program above, applied to patients with CHF and with the addition of instruction in a simple exercise program at the home visit, follow-up telephone calls at three and six months, and a telephone number for patients to call the study nurse with questions. It thus differed from many of the other disease management programs in the lack of ongoing followup and any efforts to alter lifestyle or improve stress management and coping skills. Again, variations in the patient populations served may explain these contrasts. The CHF HBI targeted hospitalized patients, aiming primarily to prevent rehospitalization over the next six months. The program's emphasis on medication compliance and symptom recognition may have addressed an important barrier in this group of patients.[18] The other disease management programs we studied target all patients with a given diagnosis in a population of enrollees. Their patients may have included both recently and not-so-recently hospitalized patients whose barriers may have differed. Thus, the most appropriate intervention included behavioral and lifestyle interventions, in addition to medication compliance.

The remaining two low-process disease management programs each heavily emphasized a single different dimension of care coordination. The first program was extremely strong in patient education and lifestyle change, the second, in medication adjustment. The first program's initial assessment includes measurements of the patient's health beliefs, propensity to comply with

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[18] A recent article reports that this program's intervention effects persist to 18 months. Earlier literature suggests that medication noncompliance is an important reason for CHF hospitalization.

treatment, self-management skills, and disease knowledge.[19] Patients were entered into 1 of 22 disease-specific care management guidelines that are evidence-based, if possible, or developed from expert physician consensus. These guidelines heavily emphasized patient self-care, including diet, patient understanding of the condition, appropriate activity level, and medications.

The other program, in contrast, spent little effort on initial assessment, education, care coordination, and service arrangement. The initial assessment took place at the office of the patient's PCP. The PCP and office staff entered patients' demographic information, medications, comorbidities, coronary artery disease risk factors (for instance, cholesterol and lipids) onto a data form. A program nurse entered this information into a computerized database, while a technician attached a 24-hour "ambulatory ischemia monitor" to the patient.[20] When the patient returned the device, the monitor readings were also downloaded into the computer software. A proprietary algorithm generated treatment recommendations, based on national guidelines and emphasizing medication management, that are designed to eliminate ischemia, lower cholesterol and blood lipids, normalize blood pressure, and increase the use of effective drugs (such as aspirin and beta-blockers). The recommendations were faxed to the PCP, and the program tracked implementation of the recommendations. The program mailed some educational information to patients on such topics as diet, smoking, exercise, cholesterol, and medications but otherwise did little additional education. The program was thus primarily a program to help PCPs optimize medication management. Program data were measured on a relatively young population (two-thirds younger than age 65) of managed care enrollees.

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[19] Questions in this area include "Can the patient explain the causes of his/her condition?" and "Can the patient explain the risk factors for graft atherosclerosis?"

[20] Ischemia is inadequate coronary artery blood flow to heart muscle tissue. Ongoing asymptomatic, or "silent," ischemia identifies patients at high risk for future coronary events.

What these programs may demonstrate is that it is possible for a strong intervention in one particular component of care coordination (patient compliance and education in the case of the HBI and lifestyle change programs, and titration of medications in the case of the ambulatory ischemia monitor program) in selected patient populations, to be effective. Clinical trial data suggest that patient education alone, or the appropriate prescription of anti-ischemic drugs alone, can have impacts on the risk of hospitalization (Lorig et al. 1999; and Ryan et al. 1999). Unfortunately, however, we cannot conclude that we can then simplify care coordination to just one or the other of these two components. We have reason to suspect that the observed results may not be generalizable to other populations, and we have no direct comparisons of a more complex intervention with a simpler one. Given the multiple gaps in care for the chronically ill described in Chapter I, it still seems best to view care coordination as a multifaceted intervention.

E. PROGRAMS WITH ZERO HOSPITAL USE/COST IMPACTS

We purposely sought out a group of care coordination programs that had high process scores yet zero hospital cost/use impacts, to see whether we could discern contrasts between them and the successful programs or use our conceptual framework to identify reasons for their lack of success.[21] We discuss five such case management programs below. In this current study, we did not find any disease management programs with high process scores and no impacts on hospital use/cost. Thus, we examine two disease management programs with zero hospital use/cost impacts from HCFA's Medicare Case Management Demonstration of the early 1990s (Schore et al. 1995; and Schore et al. 1997). These programs have only moderate process scores (9 and 13).

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[21] Recall that our attempt to examine programs with high process scores and *small* hospital cost/use impacts was unsuccessful because of the imprecision of the impact estimates. Thus, we combined all programs with high process scores and any impacts into a single group.

1. Case Management Programs with Zero Hospital Cost/Use Impacts

We studied five programs in this category. We found four in the published literature--a research study of a posthospital discharge case manager intervention in a VA Medical Center (Fitzgerald et al. 1994), a demonstration of a NP-PCP team program set in an academic medical center (the treatment or case managed group in this study actually had an increase in service use, in ER visits; Whitelaw et al. 1999), a research study of a case manager intervention in a Canadian academic medical center (Gagnon et al. 1999), and a geriatric evaluation and management (GEM) unit in a VA Medical Center (Toseland et al. 1996). The fifth program, a hospital-based program, was not part of the best practices search but had been evaluated as part of the Medicare Case Management Demonstration (this program *increased* hospital admissions; Schore et al. 1999).[22] We interviewed investigators from the Canadian study, the VA GEM study, and the NP-PCP program.

The programs generally confirmed our framework of the three steps. For example, four of the programs seemed to have difficulty with step one (Assess and Plan). One program's initial assessment did not include data on medical diagnoses, medications, important functional impairments (such as unstable gait, fall risk, and incontinence), or level of patient knowledge about his or her conditions and self-care skills. Neither did the initial assessment seek information from patients' PCPs (it was also uncertain whether patients' families were contacted). This program also used both nurses and social workers as case managers. Although we do not have enough data to say that case managers must have a nursing background, it seems doubtful that social workers in this program were able to identify patients' clinical problems and choose effective interventions in the

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[22] The first and second programs had been discovered in the best practices search and are among the ineligible programs listed in Tables II.4 and II.5 The third, fourth, and fifth programs are not included in those tables. We became aware of the third and fourth programs after the best practices search was finished, and the fifth program, from the Medcare Case Management Evaluation, was not part of the best practices search.

initial assessment and planning of care.[23] Another program's initial assessment did not include home visits, but their staff wished that it did, as they felt that home visits might have provided useful additional data. The third program identified its patients through ER visits but often could not accomplish the initial assessment and home visit for weeks or months afterward. By that time, either the patient might have made more ER visits or the original problems might have changed. A fourth program collected large amounts of data in the initial assessment, using many standardized instruments. It is not clear, however, that the GEM team then used these data to address all relevant problems in the formulation of the care plan. They did develop a care plan, but not all *specific goals* were written. One of the programs may not have *drawn on a comprehensive arsenal,* as the program's interventions consisted heavily of referrals to support services without intensive, individual education; referrals to PCPs or medical specialists (despite, for example, the high incidence of depression); or other more varied approaches. This same program also did not seem to develop *clear plans of care with specific goals* for its clients.

The programs also provided examples of shortcomings in step two (Implement and Deliver). Two of the programs mentioned difficulties in *building relations with PCPs and with other providers*. One program described itself as "invisible to physicians." The other program felt that, because of their new roles, case managers may have lacked authority and credibility with PCPs, which led to difficulty in reaching patients' PCPs. Another two programs did not provide *excellent patient education* but instead handed out printed brochures and pamphlets with little individualized

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[23] We are aware of well-conceived care coordination programs that are using staff with bachelor's degrees as care coordinators. These programs, however, did not respond to our solicitation and are not included in our study. We have also heard that one state will not renew nursing licenses of RNs working as case managers if their job description says that the position can be filled by a nurse *or* a social worker. In line with our contention that appropriate strategies depend on patient characteristics, it seems that programs serving patients with many medical barriers should use nurses as care coordinators, whereas programs serving patients with other barriers could consider care coordinators with less clinical background.

instruction or assessment of patient comprehension. Two of the programs had difficulty *making certain that planned interventions got done.* In one instance, this was because case managers were bogged down by clerical work and lobbying to get services for their patients. In the other, this was because the case manager seemed overly focused on certain interventions (such as home-delivered meals) to the exclusion of others equally important.

Finally, the programs also struggled with tasks in step three (Reassess and Adjust). One program's *periodic reassessments* were inflexible, occurring quarterly without regard to how patients were actually doing. The reassessments measured only a limited number of domains, and it was unclear whether *prompt adjustments to the plan of care* were made for patients who failed to progress or developed new problems. It was also unclear whether case managers were accessible to patients between scheduled contacts. Similarly, in another program, there seemed to be little outreach by telephone or accessibility of program staff in between clinic visits. Case managers in the program with increased ER use may not have *drawn on a complete arsenal*. The case managers came from an acute-care background. Therefore, rather than try to resolve urgent problems at home, they may have felt more comfortable sending patients to the ER, especially because this was the program whose case managers often could not reach patients' PCPs.

The NP-PCP team program experienced a number of obvious problems that prevented the performance of many of the steps and tasks. Although, with an overall process score of 16, the program seemed to be doing an excellent job in all six domains of the process scoring tool, we learned from the in-depth telephone interview about the practical difficulties the program faced. NPs were new to one of the two sites and so spent much of the initial project period establishing credibility and working relationships with PCPs, office staff, and patients. Thus, their ability to perform all three steps was disrupted. NPs were well established at the other site, but only as primary care providers. They were asked to assume the new care coordination duties. Not surprisingly, without relief from their already busy practice responsibilities, they also could not do a good job in the three basic care coordination steps. For example, although the NPs were supposed to administer a comprehensive set of instruments in the initial assessment, in practice they often left out various instruments if they were pressed for time and the domain did not seem an “obvious” problem. Similarly, time was constrained for care planning, implementation and delivery of the care plan, reassessment, and adjustment.

There are other possible explanations for the lack of impact of some of the programs. The VA and Canadian programs pointed out that, because access to care for the chronically ill in their respective health care systems is relatively unrestricted, the care received by the treatment groups may not have been different enough from that of the control groups to have caused impacts. More important, during the period of the Canadian study, changes were being made to the usual care system that made it resemble the treatment provided to the experimental group. Finally, we note that all three of these programs were research or demonstration projects of limited duration. Although several other research studies included in our investigation were able to show impacts, such limited-duration projects do run the risk of what the Canadian program called “short-timer syndrome”--that is, that patients and PCPs do not take a “temporary” program seriously enough to alter their behavior. Alternatively, the problem may have been that the programs were not in operation long enough or patients followed long enough for impacts to occur. Establishing the necessary relationships with PCPs and refining care coordination protocols take time, and therefore are often lacking in programs that are newly implemented.

2. Disease Management Programs with Zero Hospital Cost/Use Impacts

The two programs in this category were both from the Medicare Case Management Demonstration, and thus not part of the best practices search. One program focused on CHF, the other on CHF and chronic obstructive pulmonary disease (COPD).

In each step, both programs differed in a number of ways from those disease management programs that did have favorable use/cost impacts. For example, as part of the initial task of *uncovering all important problems,* the other disease management programs used evidence-based national guidelines to compare patients' current treatment and status with the optimum. In contrast, neither of the zero impact programs explicitly incorporated any national guidelines in this task. The CHF and COPD program did not, in fact, seem to gather much data at all on symptoms, medications, diagnoses, or patient behavior and knowledge in the initial assessment, but concentrated instead on mental status and activities of daily living. Although such information is important, it may not be adequate to identify *all* barriers to improved health, especially for CHF and COPD patients. This program also used a mixture of registered nurses (RNs) and licensed practical nurses (LPNs) as care managers. Again, we cannot say for certain that all care managers must be at least RNs, but we suspect that LPNs may not have the clinical sophistication to be able to recognize and handle important needs that this group of seriously ill patients may have. Neither program performed home assessments, which some of the other programs found helpful for heart failure patients.

The lack of guidelines and protocols also hampered the task of *addressing all important problems*. Although one program did collect fairly comprehensive information in the initial assessment (including symptoms, medications, comorbidities, ability to monitor symptoms, smoking, and drinking), it is unclear that this information was used in any systematic manner to develop a care plan. This contrasts with many of the other disease management programs that used sophisticated decision support software to guide care managers in the development of care plans.

Neither program seemed to have in its arsenal the other programs' intensive education to modify patients' behavior. One program developed a *care plan with specific goals,* but the other did not.

These two programs also fell short in several areas of step two, Implement and Deliver. Although we have said earlier that, compared to case management programs, disease management programs seemed to place less emphasis on the relationship with PCPs, these two programs appeared to have virtually no relationship with them at all. One program's only contact with physicians was an occasional call to an office nurse to request orders for such services as oxygen, home health care, or durable medical equipment. This program's *relationships with other health care providers* were also characterized by frank hostility from hospital discharge planners and home health agencies. The other program also had essentially no contact with PCPs. The program attempted some educational mailings to PCPs on the optimal use of angiotensin-converting enzyme inhibitors in CHF patients; however, it is unclear whether the mailings were ever seen by the PCPs. Neither program seemed to develop the "coach," "cheerleader," or "personal trainer" *relationship with patients* mentioned by some of the other programs. As stated earlier, neither had the degree of educational intensity seen in the other programs. The programs seemed unable to *make certain that planned interventions got done* (whether the intervention was a test, an appointment, an increase in medication dosage, or a lifestyle change), as many of the successful programs did, especially with computerized tracking software.

The programs' problems in step three, Reassess and Adjust, seemed to lie in the completeness of the first task, *periodic reassessments,* and the last task, *make prompt adjustments to the plan of care*. Although both programs adjusted the frequency of calls to the sickness of patients, and one program gathered data in a structured fashion, it is unclear that these telephone calls generated useful modifications to the care plans, such as an urgent home health visit or a call to a physician's office to adjust medications. Finally, it is unclear that the accessibility task was addressed; the evaluation did not mention whether either program had a system for patients to reach care coordinators in between scheduled contacts.

3. Summary

In general, the experience of both case management and disease management programs with zero hospital use/cost impacts seem consistent with the framework of steps and tasks. There is evidence that each program had difficulty successfully accomplishing tasks within each step, which might explain their lack of impacts. However, the programs seemed to fail for a range of reasons; no single reason emerges as critical for the success of a care coordination program.

F. OTHER IMPORTANT TYPES OF PROGRAMS

This section discusses programs that target adult Medicaid beneficiaries, people with disabilities, and those with severe and chronic mental illnesses. These populations are of great policy importance, but none of the programs that serve them were included among the set that was interviewed in detail, due to lack of evidence of impacts or low process scores. There is a great deal of overlap in these populations, so that a discussion of programs for physically disabled and mentally ill persons would include programs for Medicaid beneficiaries. Another condition prevalent among Medicaid beneficiaries for which coordinated care programs have been developed is AIDS. We thus organize this discussion into four types of coordinated care programs: (1) programs for people with severe physical disabilities, (2) programs for people with chronic mental illness, (3) programs for people with AIDS, and (4) programs for "general" adult Medicaid beneficiaries without any of the preceding three conditions.

1. Programs for People with Severe Physical Disabilities

Community Medical Alliance (CMA), described in detail in Masters (1998), is the only well-described coordinated care program of which we are aware for severely physically disabled people, and it was, in fact, one of our eligible programs. It was not selected for the final group for further study, because its evidence score fell below the minimum level of four.[24] The program is fully capitated by the Massachusetts Medicaid program. To be eligible for the program, patients must have functional quadriplegia from any cause.[25]

The program is based on a team model. There is a small panel of full-time PCPs and NPs, and each patient is assigned to an NP-PCP team. The NP plays a key role, providing both clinical care and case management. The NP performs comprehensive initial assessments and, in consultation with the PCP, selects and coordinates such services as mental health, social services, home health care, physical therapy, and hospital discharge planning. The NP monitors patients' progress with home visits and frequent telephone calls; offers reassurance, guidance, and support; and provides urgent and routine clinical care both in the home and in the office or ER. The program takes a proactive approach, emphasizing the timely provision of services to prevent complications such as pressure ulcers, urinary-tract infections, or respiratory infections. There are weekly team meetings to discuss both active cases and cases due for periodic review. In addition to office care, PCPs also provide home visits and inpatient care (as opposed to inpatient care by medical residents and faculty

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[24] It had medium overall impacts, an evidence score of three, and a high-process score.

[25] The typical causes were spinal-cord injury, traumatic brain injury, cerebral palsy, muscular dystrophy, end-stage multiple sclerosis, or Huntington's disease. An alternative eligibility criterion listed in an earlier article but not in a later one was having a condition that requires at least 10 hours per week of personal assistance services for activities of daily living (ADLs) or at least 14 hours per week of personal assistance for instrumental activities of daily living (IADLs). The need for personal assistance services was defined by the state Medicaid agency and based on the number of permanent dependencies in ADLs and IADLs.

physicians). To foster familiarity and closer collaboration between inpatient hospital staff and program staff, CMA arranged for its patients always to be admitted to the same hospital floors and established a nurse liaison to monitor the hospital care of its patients during the day. The program has NPs and PCPs available by telephone 24 hours a day, seven days a week. The program points to the development of close personal relationships between NPs and clients as crucial to the program's effectiveness, fostered in large part through the NPs' home visits.

2. Programs for People with Chronic Mental Illness

a. Program of Assertive Community Treatment (PACT)

PACT is a model of mental health service delivery that aims to improve care, improve functioning (in employment or school settings and in social and interpersonal relationships), improve integration into the community, and reduce repeated hospitalizations for persons with severe chronic mental illness. Since PACT was first described in the early 1970s, it has been studied extensively through numerous randomized and nonrandomized studies. There have also been a number of major research syntheses (Burns and Santos 1995; and Mueser et al. 1998). A full discussion of PACT is beyond the scope of this report, but we provide a brief description here (National Alliance for the Mentally Ill Web page, Jan. 6, 2000).

PACT serves adults with severe, disabling, persistent mental illnesses, such as schizophrenia and other psychotic disorders, and bipolar disorders. Clients often have coexisting problems, such as homelessness, substance abuse, and involvement with the judicial system. Funding is usually through state Medicaid programs. Care is provided by a multidisciplinary team consisting of psychiatrists, nurses, social workers, vocational rehabilitation therapists, and other mental health workers. A careful, individualized initial assessment is made to define clients' needs, establish treatment goals, and select interventions to meet those goals. Clients undergo ongoing assessments to see how they are progressing. To meet the needs of their clients, the team offers, in one place, a wide array of services, including prescription and monitoring of psychiatric medications, coordination with other medical health care services, hospital care, individual counseling, client education in the illness and its treatment, cognitive-behavioral and other behavioral therapies, crisis intervention, substance abuse treatment (including group therapy), support for employment and education, family education and counseling (including assistance to clients with children), and service referrals (for example, for legal services, children's advocacy, financial support, money management, housing, and transportation). Clients can call program staff 24 hours a day, seven days a week. Services can be provided in peoples' homes, in the local community, or at the workplace.

A recent review of randomized trials conducted since 1990 concluded that there was strong evidence that PACT was effective in reducing psychiatric hospital use, although the effect was somewhat greater on length of stay than on number of admissions (Burns and Santos 1995). In its recent report on evidence-based treatments, the Schizophrenia Patient Outcomes Research Team also included PACT among its recommended treatments (Lehman and Steinwachs 1998). There are currently six statewide PACT programs, and 19 states are sponsoring pilot programs (National Alliance for the Mentally Ill Web page, Jan. 6, 2000).

b. Managed Behavioral Health Organizations

Managed behavioral health organizations (MBHOs), which "carve out" mental health care and substance abuse treatment from general health care, are recent innovations that claim to reduce costs. Such organizations contract with payers (self-insured employers, HMOs, Medicaid agencies) to manage behavioral health benefits. A behavioral carve-out in the Massachusetts Medicaid recipients appears to have reduced costs (Callahan et al. 1995; and Frank and McGuire 1997), and there are some preliminary data on the performance of these organizations in commercially insured populations (Goldman et al. 1998; and Huskamp 1998). Furthermore, it appears that MBHOs' impacts may be due primarily to better utilization review and utilization management, more favorable negotiated rates with providers, and improved reimbursement methods that create incentives for providers to substitute outpatient and drug treatment for inpatient care, rather than from any new care coordination programs per se (Ma and McGuire 1998).

3. Programs for People with AIDS

The developers of the CMA program for persons with severe physical disability also developed a program for Medicaid beneficiaries with advanced AIDS, defined as AIDS with one or more opportunistic infections or malignancies (Master 1998).[26] The CMA AIDS program is also paid through capitation by the state Medicaid agency. Some data suggest that the program may have reduced hospitalizations. Unlike in the program for the severely disabled, patients' primary care doctors are not CMA staff, but are in practice all over the city, so the program does not function on a team model. Patients are still assigned an NP, but the NP works with whichever PCPs are caring for enrolled patients. In addition to providing clinical care, the NPs perform many of the case management functions as in the other programs we studied: assessing patients needs, working closely with patients' PCPs, making home visits, instructing in self-care, dealing with social and psychological problems, arranging for services, and coordinating medical and nonmedical care. Again, the program's emphasis is on providing services early to avert problems later on.

Other AIDS case management programs have been developed through state Medicaid AIDS waivers. Five of these programs are reviewed in a recent report (Schoff and Schore 1997). Of the

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[26] The CMA AIDS program had small overall impacts, an evidence score of two, and a high process score.

five, only a New Jersey state program reported data on inpatient use. The data were inconclusive but suggested that the program may have decreased hospital use.

4. Other Coordinated Care Programs for Medicaid Beneficiaries

a. Medicaid Programs from the Best Practices Search

We did hear of two promising state Medicaid programs in Maryland and West Virginia. The Maryland Access to Care (MAC) program, which focused on Medicaid beneficiaries with common costly, chronic illnesses such as diabetes and asthma, claimed some favorable impacts on health care use. A published evaluation found, however, that the program increased Medicaid expenditures (Schoenman et al. 1997). That version of the program has been discontinued, and the current version of the program, now called the Rare and Expensive Case Management Program (REM), focuses on rare and costly conditions primarily affecting children, such as phenylketonuria, leukodystrophy, Friedreich's ataxia, Kugelberg-Welander disease, and spina bifida. The current director of the REM was also the director of the MAC program. We contacted her office during the best practices search but did not receive a call back from her. We also contacted the state Medicaid office in West Virginia, but that call was not returned.

b. Medicaid Primary Care Case Management (PCCM)

PCCM was a program innovation introduced into FFS Medicaid programs in the 1980s to control rising Medicaid costs (Holahan et al. 1998). Under PCCM, PCPs receive a small fee per enrolled patient to perform gatekeeping and care coordination services. Although PCPs are expected to provide some extra services, PCCM does not appear to be a true coordinated care program by our definition in Chapter I. Many states adopted PCCM, but with little evidence of reduction in hospital use (Hurley et al. 1989; Schoenman et al. 1997; and Buck and Silverman 1996). Under PCCM, PCPs are not at risk for medical costs and have little incentive to control service use. As states have moved increasingly toward managed care for their Medicaid programs, PCCM has gradually fallen out of favor, except in rural areas where managed care is difficult to implement (Holahan et al. 1998).

5. Summary of Programs for Disabled, Mentally Ill, and Medicaid Recipients

Although we did not study coordinated programs serving these important populations in depth, in our brief review we discovered many of the same features and themes as we found in our examination of other programs. Successful programs, such as PACT, seemed to follow the same three-step process of assessing patients' needs and planning care, implementing and delivering services, and reassessing and adjusting the plan. Programs tried to bring a wide array of interventions to bear on patients' problems, emphasized the importance of the patient-case manager relationship, and took a proactive approach of providing services early to prevent complications later. However, few were evaluated with designs that provide convincing evidence that programs affected costs.

V. DISCUSSION

In this chapter, we draw some broader conclusions from the detailed observations in Chapter IV. We start with some comments on care coordination in general, then we consider the limitations and strengths of this study. We conclude with a discussion of the implications of the study findings for the demonstration.

A. GENERAL COMMENTS ON CARE COORDINATION

1. Gaps in the Current Health Care System

It is widely believed among researchers, policymakers, consumers, and even providers that because the skills and strengths of providers are primarily in the diagnosis, treatment, and rehabilitation of acute illness, the traditional U.S. health care system often does not meet the needs of people with chronic illness. Although providers do currently supply some elements of care coordination, they generally do not offer the services we found in this study: comprehensive multidimensional assessment of medical, functional, and psychosocial needs; arrangement of community services; coordination across providers; intensive health education and support for lifestyle modification; and methodical tracking of patients' progress between office visits. The programs described in this report are consistent with and confirm the working definition of "care coordination" laid out in Chapter I.

2. Case Management and Disease Management Programs

Our study suggests that there are two main populations of chronically ill patients and two corresponding and equally important types of programs that have evolved to serve them: case management and disease management programs. Case management programs serve the smaller group of patients that are at high risk because of various complex medical or social problems. Because these patients are fewer in number and present diverse combinations of problems and needs, case management programs can and must carefully assess each patient and develop highly individualized plans of care. In contrast, disease management programs serve the larger group of patients whose *main* problem is a single chronic disease. These patients are more numerous, but they tend to have similar primary needs. For example, regardless of other comorbidities, all heart failure patients need to have optimal heart failure medications prescribed, to take these medications consistently and to monitor their weight and symptoms. Thus, disease management programs can and should take a more standard approach with each patient than case management programs do. Care planning often starts with a template that is then modified to fit the individual patient.

There may be some overlap between the two target populations. There are no unambiguous definitions of "high risk" (the patients targeted by case management programs). Rarely do people with a given diagnosis (the patients targeted by disease management programs) have only that diagnosis, without at least one or two comorbidities. Empirically, however, we found important differences between the two types of programs, and thus we believe that the distinction is useful and that both types of programs are needed.

3. Similarities and Differences Across Programs

We also found that even within each broad category of program, there are many effective ways of coordinating care, which again reflect the characteristics of patients served. For example, depending on the target population, omission of a routine assessment of nutritional status may not adversely affect patients of one program but may cause another program to miss critical patient information frequently. As another example, some programs discharge patients after a set period of time; other programs never discharge patients. The appropriateness of the presence or absence of each program element and how it is delivered must be judged by whether the particular step or task to which it is aimed is accomplished for the specific patients served. Such judgments, in turn, depend on having an accurate picture of the patient population.

Despite the variation in approaches, we did find several common and recurrent themes. All the successful programs went through a three-step process with each patient--step one, assessing the patient's needs and goals and developing a plan of care to meet them; step two, implementing the plan of care and delivering services; and step three, reassessing the patient's progress and adjusting the care plan as needed.[1] Although the details of how the programs accomplished each step varied according to the target population, the program's setting, and various other factors, some component tasks within the three large steps did remain constant: (1) the production of a written plan of care at the end of step one, (2) the establishment of an ongoing care coordinator-patient relationship and the provision of comprehensive and effective patient education about self-care in step two, and (3) a periodic reassessment and monitoring of patients in step three. Disease management programs all relied heavily on national, evidence-based, or consensus-based guidelines for the care of their disease. In all the programs, a proactive approach also underlay these steps and tasks, an approach that emphasized preventing and averting adverse outcomes in the future by the timely provision of services in the present. All the programs we studied used case managers and disease care managers with at least a bachelor's degree in nursing, some with additional master's level training.[2] Finally,

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[1] Of course, programs had to find their patients first. They all had criteria for program entry, some quite broad and implicit, others more narrow and explicit. The methods with which they found patients varied widely, depending in great part on their setting (Appendix D).

[2] Although we are aware of carefully conceived care coordination programs that are using non-nurse care coordinators with bachelor's degrees, these programs did not respond to our solicitation and are not included in this study.

all the effective programs studied in depth had considerable experience in care coordination, with a mean age of 4.5 years.

We learned that successful rural programs accomplished the steps and tasks using the same tactics as the other programs. However, the long distances placed constraints on the case management process. Case managers had to limit their caseloads, had difficulty maintaining relationships with outlying doctors, and had to spend much time and effort on transportation issues. Having case managers with close ties to the community and in-depth knowledge of community resources seemed especially important in rural areas.

4. Comparison with Previous Work

Although we have taken a somewhat different approach by tracing through the process of coordinated care to arrive at the three key steps, our findings agree with those of other researchers who have attempted to identify the critical elements of care coordination. For example, Wagner et al. (1999) identify four key features:

1. Self-management support--instruction on behavioral and lifestyle change (diet, exercise, smoking, and alcohol), attention to the emotional stresses of illness, and development of patients' confidence and skills to become ultimate managers of their own illness
2. Decision support--implementation of evidence-based guidelines, provider education, reminders, and increased interaction between generalists and specialists
3. Clinical information systems--tracking systems, reminders, planned care, feedback
4. Community resources and policies--supportive or educational services in the community

These activities are each identified in our framework as tasks to be accomplished or tools to be used in developing a care plan, implementing the plan, and making needed adjustments to the plan over time.

Our findings also agree with those of others that coordinated care has the potential to reduce health care utilization while maintaining or improving quality of care (Rich 1999; and Philbin 1999). These results should reassure those concerned that efforts to reduce costs risk lowering quality (Wagner et al. 1996; Wagner 1998; and Bodenheimer 1999). We have noted the proactive approach of the programs we studied. Care coordinators in most programs viewed themselves as advocates for their patients. The proactive approach is consistent with the Case Management Society of America's description of "a collaborative process which assesses, plans, implements, coordinates, monitors, and evaluates 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 1995). The programs we studied thus contrast with utilization review/management programs (sometimes confusingly called "case management programs"), which generally take a *reactive* approach of involvement only after a problem has already occurred. Utilization management programs have been said to "manage the benefits"; that is, their focus is on determining whether a service constitutes a covered benefit, whether criteria for coverage have been met, and whether the service is the most cost-effective option among those available. Care coordination, in contrast, "uses benefits to manage"; that is, the focus is on using all appropriate benefits (and possibly supplementing them, such as with community resources) to help patients overcome barriers to health and attain the goals in their plan of care.

Our findings suggest that incremental approaches to improving chronic illness care can succeed. There is nothing in the three steps or in the overall proactive stance that requires any particular organizational or structural change in the health care system. That is, with the exception of the "team programs," the programs in our study did not require physicians to hire new staff, install new equipment, or reorganize their practices. Incremental approaches contrast with approaches of "delivery system redesign," which feature addition of new staff and resources, reallocation of roles, and reorganization of offices as prerequisites for effective chronic care (Wagner 1996; and Wagner et al. 1999). Nor did the programs we studied require patients, hospitals, physicians, or other providers to restrict themselves or be "locked in" to a predefined network of providers.[3] This, too, contrasts with calls for horizontally and vertically integrated service networks as being the preferred way to improve chronic care (Bringewatt 1995). Although such major changes might well lead to great improvements in care, they would be difficult to implement in the traditional Medicare fee-for-service (FFS) system--still the health insurance for the vast majority of senior Americans and a program with relatively unfettered choices for both patients and providers.

Programs also were able to achieve positive impacts without taking chronically ill patients away from their primary care physicians (PCPs), the so-called "carve-out" approach, which has been criticized by Wagner et al. (1996) and Bodenheimer (1999). Except for the relatively small number of team programs, the programs in our study instead maintained the primacy of the traditional PCP-patient relationship.

B. LIMITATIONS AND STRENGTHS OF THE STUDY

1. Limitations

Our study's reliance on self-reported data may have affected both generalizability and internal validity. The process and evidence scores, which were used to select programs for interview, were based on information furnished by programs themselves, and we have no independent means of verification. However, information on both process of care and impacts from that of unpublished programs did not seem to differ markedly or systematically from published programs. (Although

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[3] Although some of the programs we examined were in HMO settings where patients are locked in, many were in FFS environments.

even peer-reviewed articles are not completely error-proof, their results should be more trustworthy.) The detailed interview data were also provided by program staff. The interviews were conducted, however, by two objective interviewers with extensive case management experience who sought to obtain an accurate picture of program operations. Furthermore, our observations on the three major steps, the important component tasks, and the programs' proactive philosophy appear quite broad-based across the programs, are supported by evidence from non-interviewed programs and a small number of programs we studied with zero use/cost impacts, and are consistent with the conclusions of other authorities on chronic illness care.

Questions about generalizability also arise because of our volunteer sample and our exclusion criteria. Only programs willing to respond to the substantial information requests of our solicitation were included (as noted in Chapter II, a significant number of programs never responded). We excluded those without evidence of favorable impacts on hospital admissions or total medical costs. We may thus have excluded a number of highly regarded coordinated care programs. Despite this limitation, it is not likely that including additional programs would have altered any of our basic conclusions. At most, the inclusion of more programs would only have provided alternative detailed examples of *how* to accomplish the steps and tasks.

We were also unable to address program cost-effectiveness. Few programs had any actual data on their operating costs, and what data existed were of poor quality. Furthermore, because program costs are affected by economies of scale and other factors, our main goal was to find programs with at least some credible evidence of reducing hospital admissions or medical costs.[4] The impacts

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[4] Cost-effectiveness in some cases may be more a function of patient targeting than the actual program efficiency itself. An extremely effective program may appear to have poor cost-effectiveness if it is poorly targeted and therefore serves large numbers of people who do not benefit from the intervention.

observed for most of these programs are sufficiently large to cover fairly sizable program costs. Hence, it is likely that many, if not most, would have generated savings that exceeded the intervention cost. Research on the cost-effectiveness of these types of programs will have to await the demonstration.

Some of the programs we studied had managed care or integrated system features that might not translate to a Medicare FFS setting. A few of the large disease management programs, for example, may operate in managed care organizations that exert influence over contracted PCPs through the threat of exclusion or through contractual clauses that compel cooperation with such activities as guidelines or office chart reviews. None of the case management programs, however, and few of the remaining disease management programs seemed to rely on such features. Indeed, instead of coercion, some programs used persuasive strategies, such as recruiting respected local clinician opinion leaders to convince colleagues to participate, making presentations at hospital conferences, and building strong relationships between care coordinators and PCPs. Thus, we have no reason to believe that control over physician and patient behavior, such as that held by plans or integrated delivery systems, is critical to successful implementation of care coordination.

A few of the large disease management programs also took advantage of health plan encounter and pharmacy data to determine whether a diabetic had her eye doctor visit or a patient filled his heart medication. Demonstration programs are not likely to have access to similar data.[5] Perhaps useful physician performance profiles could still be compiled using patient self-reported data or with

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[5] It is unclear whether HCFA will be able to make claims data available to demonstration programs or whether these data would be available rapidly enough to be useful for care coordination. Since Medicare FFS does not cover prescriptions, there are no pharmacy data in Medicare claims data.

a minimal amount of assistance from physician office staff. These sources are potential alternatives to encounter data for determining whether services were delivered.

A final limitation is the impossibility of completely isolating “pure” program features that might contribute to program effectiveness from underlying factors inherent in programs’ organizational or reimbursement environments, especially where there was little variation in such factors across programs. Examples of such underlying factors include the presence of incentives and the availability and quality of primary care.

Only one of our programs had no obvious immediate financial or nonfinancial incentive to reduce hospitalizations. This program was a hospital-sponsored freestanding senior health center that had been financed through Medicare’s reimbursements for hospital outpatient services (prior to the reductions of the Balanced Budget Act of 1997). For the programs established in risk-bearing managed care organizations or provider organizations, there were clear financial incentives to contain costs. Incentives for investigational programs designed to demonstrate the effectiveness of care coordination might include the satisfaction of confirming the research hypothesis and gaining academic recognition. Furthermore, many hospital-based systems and academic medical centers indicate that they would be uninterested in participating in a demonstration that, if effective, would result in a substantial loss in revenue from medical care. Financial incentives for generating savings in Medicare costs could overcome this major objection. Our previous experience with the Medicare Case Management Demonstrations, and the comments on the financing of care coordination received as part of the Public Comments solicitation (Appendix A), all suggest that financial incentives play an important role in the success of care coordination programs.

All the programs did presuppose a basic infrastructure of adequate primary care. Most of the programs were designed around a care coordinator who worked with patients and their PCPs. None of these programs would probably function well in areas where patients cannot gain basic access to a PCP. Due to insufficient data, another potentially important issue that we are unable to address is whether there is any interaction between care coordination and primary care physician specialty. For example, program effectiveness might vary by whether primary care physicians are generalist physicians (general internists, geriatricians, or family practitioners), versus specialist physicians caring for patients with problems in their specialty area, versus specialist physicians caring for patients with problems outside of their specialty. Also unknown is whether case management and disease management programs would exhibit the same differential effects by physician specialty.

2. Strengths

Our study of coordinated care programs also has a number of unique features that enable us to make more general inferences about effective care coordination than some other surveys do. First, we based our study only on programs with documented, credible evidence of program impacts. Our assessment of program evidence not only incorporated the sizes of estimated impacts, but also gave greater weight to higher-quality study designs. We are unaware of any previous reviews that have limited themselves to programs with demonstrable impacts, nor do we know of any previous studies that have considered the strength of programs' evidence for impacts.

Second, our study explicitly acknowledges the practical consideration of program costs and savings. Although we had no measures of actual program cost-effectiveness, we did focus on programs that reduced either total medical costs or numbers of hospitalizations (the most expensive medical service), because only such programs stand a reasonable chance of being cost-effective. Programs that demonstrate only improvements in clinical processes of care are an important contribution, but unless they can also be shown to save at least as much money as they cost, they will only add to the problem of escalating health care costs.

Third, unlike previous studies, by setting forth a working definition of what "care coordination" is, and by considering the long-range interests of the Medicare program, we excluded two kinds of so-called "case management" programs that are sometimes included in reviews of care coordination programs. The first kind, developed mainly by hospitals, has a primary goal of shortening inpatient hospital stays. The second kind are the reactive utilization review/utilization management programs mentioned earlier. Neither type of program tries to meet the needs of chronically ill people that current health care fails to address, and neither type of program typically takes the long-range proactive approach of intervening now to avert poor outcomes in the future.[6]

Fourth, our review had a broad scope. We considered both case management programs and disease management programs under the umbrella term "coordinated care," and we pointed out useful distinctions *and* similarities between the two. In particular, we noted that the two types of programs both go through the three large steps (Assess and Plan, Implement and Deliver, and Reassess and Adjust) and that both types of programs adopt a proactive approach. We observed, however, that "high-risk" patients and patients with a primary disease seem to have differing needs, and that these contrasting needs shape the details of how the programs approach the three steps. Previous studies have tended to restrict themselves either to case management or to disease management programs (together without recognizing any differences between them (Wagner et al. 1999). Our study also included coordinated care programs regardless of the setting or sponsor, and programs ranged from those in FFS settings to those in nonprofit managed care organizations to those sponsored by for-profit commercial vendors. Other studies have generally examined only programs developed in Medicare managed care risk plans (Pacala et al. 1996).

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[6] These programs are proactive about avoiding adverse short-term outcomes, such as prolonged hospital stays. An example of such intervention would be scheduling a series of radiology tests in the most efficient sequence.

Finally, perhaps because our study took a somewhat more empirical approach than previous work to uncovering effective care coordination approaches, our conclusions may have broader applicability. Although we did start with a loose working definition of care coordination, we had neither any clearly defined model of what coordinated care programs must look like nor any list of essential features of such programs. Thus, as noted earlier, we do not necessarily find any organizational (integrated versus nonintegrated delivery system, for example), financial (FFS versus capitation, for example), or procedural (one type of assessment instrument versus another, for example) restrictions on how programs can accomplish the three steps and their component tasks and successfully adopt a proactive philosophy.

C. IMPLICATIONS FOR THE DEMONSTRATION

Our study suggests that a demonstration in FFS Medicare of coordinated care programs similar to the ones we studied is feasible and appears to have a reasonable chance of being cost-effective. Based on common themes and features in the programs studied, and on the demonstration's importance for the Medicare program in particular, we make the following five recommendations for features of demonstration programs:

1. Programs should follow the three steps (Assess and Plan, Implement and Deliver, Reassess and Adjust) for all enrolled patients.

    - Step one should conclude with a written plan of care.

    - Step two should include the establishment of an ongoing care coordinator-patient relationship and the provision of comprehensive patient education about the patients' condition and self-care.

    - Step three should include periodic reassessment of patients' progress.

2. Programs should have expressed goals of prevention of health problems and crises, and of early problem detection and intervention (a proactive approach, in other words).

3. Disease-specific programs should incorporate national evidence-based or consensus-based guidelines into their interventions.
4. Care coordinators should be nurses with at least a bachelor's degree in nursing.
5. Programs should have significant experience in care coordination and should have evidence of reduction of hospital use or total medical costs.

We also note that many of the programs we studied have the above characteristics but do not disrupt or carve out existing PCP-patient relationships and do not require "lock-in" to restrictive provider networks. Therefore, no such restriction should be necessary for a successful Medicare FFS demonstration.

Given the time constraints of the demonstration and the length of time it takes programs to build relationships and establish procedures, we felt that significant experience and evidence for favorable impacts on hospital use/cost were particularly important program requirements. Even experienced programs with evidence of impacts will face some challenges in adapting to the Medicare FFS environment. Programs that are just starting would need to hire and train inexperienced staff, design clinical protocols, develop methods of finding and enrolling patients, build relationships with providers, and establish smooth operations. New programs would thus be even substantially less likely than established programs to be cost-effective in the short time period likely to be covered by the demonstration.

We are reluctant to recommend any longer list of minimum criteria for demonstration programs. Our findings suggest that it is important to avoid the trap of "more is better"--the assumption, for example, that an initial assessment in person is always better than one by telephone or that weekly monitoring is invariably better than monthly monitoring. The costs of the "more is better" approach can rapidly exceed its benefits.

We also recognize that our study does not allow us to conclude that a care coordination program *must* have the above features to be successful as a Medicare demonstration. On the other hand, we found little evidence to suggest that programs missing several of these features would have a high likelihood of success. Unless a program can provide convincing evidence of success in a different setting or population and lower costs, our evidence suggests that programs possessing more of the core features above should be viewed more favorably than those with fewer features.

Implementation of a care coordination demonstration in FFS Medicare raises a host of difficult design issues, which will be addressed in a separate demonstration design report. Such issues include detailed requirements for bidding organizations, methods of paying demonstration programs, specification of potential outcome measures, and sample size calculations.

D. SUMMARY

In summary, our study's findings are promising for designing a successful demonstration for care coordination in FFS Medicare. We have developed a simple conceptual framework and some minimum recommendations for the selection of program models to be demonstrated. Our findings suggest that care coordination holds the potential to reduce health care utilization while maintaining or improving the quality of care for chronic illness within the existing health care system. What remains to be seen in the demonstration is whether care coordination programs achieve the same medical cost savings and quality impacts in a Medicare FFS setting and whether the savings will exceed the cost of the intervention.

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APPENDIX A

PUBLIC COMMENTS

Besides the identification and study of successful coordinated care programs, another important element in the Best Practices Study was a process to collect public comments. The goal of this effort was to invite interested parties to share with us their knowledge and opinions about best practices and the demonstration. HCFA's notice in the *Federal Register* of March 23, 1999, the Best Practices Study Web site, and the letters we mailed out, all contained the following language:

> [We request] comments on potential aspects of the overall demonstration...that discuss and distinguish program characteristics known to be essential for positive outcomes in a fee-for-service setting. Commenters may also wish to address the types of providers, organizations, or entities capable of, and qualified to provide, coordinated care or case management services. Other aspects of importance include, but are not limited to:
>
> - The relationship of the case management entity with other providers
> - The potential role of the case manager in authorizing or providing services beyond coordinating and educational activities
> - Appropriate incentives for the case management entity, beneficiaries, and other providers
> - Appropriate payment methodology
> - Potential risk bearing arrangements for the case management entity
>
> In addition, we seek comments regarding challenges to, and potential solutions for, implementing a coordinated care demonstration in rural sites.

Twenty-five organizations, all but six of which were care coordination programs, provided comments on the above issues. Although the comments that programs submitted tended to focus on how the specific features of their own programs embodied essential program characteristics, some of the programs did discuss the features that they believed should be exhibited by a best practice program. Below we describe and discuss the general themes covered by the comments.

A. KEY FEATURES OF CARE MANAGEMENT ORGANIZATIONS AND PROVIDER ROLES

Comments on which type of organizations are most capable of providing care coordination services tended to be influenced by the characteristics of the commenting organization, and by the characteristics of the patient population. Case management programs focused in the needs of high risk patients, while disease management programs focused on the needs of patients with specific diagnoses. For example, commercial vendors believed that independent organizations were best suited for providing care coordination services, whereas integrated delivery systems believed that integrated health systems could best implement coordinated care. A few common themes did emerge, however.

1. Organizations Best Suited to Provide Care Coordination Services

An organization with a particular interest in persons dually eligible for Medicaid and Medicare submitted comments listing what they see as some basic responsibilities of the coordinated care organization: (1) developing good communication among providers, (2) training providers about the roles and responsibilities of each member of the care team, and (3) establishing consistent goals across a patient's providers. This organization believes that achieving good care, services, and outcomes requires a system that facilitates, rewards, supports, and reinforces provider collaboration. The efforts of the programs we studied are consistent with all of these points.[1]

Another key to success that was identified by this organization and exemplified by the successful programs we interviewed is the ability of the program to encourage collaboration among

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[1] The second point mentions a care team, but whether or not there is a formal team, as in the team programs, or a "de facto" team, as in the non-team programs, it is important for PCPs to understand and accept the care coordinators' role.

care providers. As this organization pointed out, collaboration can offer many benefits, including the development of:

- Protocols for transition of care between providers
- Centralized patient-tracking systems or databases (as opposed to multiple, unshared databases)
- Mechanisms to keep the consumer active in decision making
- Opportunities to have providers see each other face-to-face
- Protocols and mechanisms to exchange information among providers

Several other organizations commented on the need for an integrated approach to care. One disease management vendor said that care coordination programs should be based on the fact that the majority of patients needing care coordination services have one or more complex illnesses, meaning that programs should offer cost-effective, long-term support, not episodic management with predetermined discharge points. Another disease management vendor agreed, saying that care coordinators should manage high-cost, high-risk, chronically ill Medicare beneficiaries using an integrated approach that addresses patients' multiple comorbidities and usage of health care services. This second program believes that disease management companies are uniquely capable of and qualified to provide these services because these providers have the information systems and personnel to make long-term monitoring feasible and cost-effective. A case management program in an integrated health system noted, however, that frail elderly patients with multiple medical and social problems do not fall conveniently into one disease process, and therefore believed that these patients would be ill served by most current disease management programs. They believed that these patients would be better managed by a larger system with access to a larger number of specialty providers.

Another organization suggested that organizations providing care coordination services must have the ability to (1) identify the at-risk population, (2) use proven methods of disease management and case management implementation, (3) continuously monitor patients, (4) measure and report outcomes, and (5) directly interact with patients. Their summary of program competencies agrees, in fact, with our three-stage model of care coordination (Figure III.1) and their recommendation to use "proven" methods is consistent with our recommendation that programs selected for the demonstration should have evidence that they are effective.

One organization emphasized that care coordination should focus on psychosocial aspects of care for the chronically ill, not just on clinical issues. They point out that depression is a primary factor in high utilization of medical services, and that the major reason why people enter a nursing home is because their support system is exhausted or nonexistent. Although our report focused on programs successful in reducing hospital use, all the programs included psychosocial issues in their initial assessments to varying degrees, depending on the characteristics and needs of their patients.

One diabetes disease management program recommended that disease management programs should be able to handle patients' comorbidities: "We have found that it is essential that the disease state be used as an entry criterion, but then to integrate all their health care after they are in. Diabetics, with their multiple problems, are especially prone to falling between the cracks." The data we have examined for the demonstration design report confirms that most Medicare beneficiaries who would be included in the patient populations of disease management programs (such as those with diabetes or congestive heart failure) do suffer from multiple chronic medical conditions. Disease management programs that exclude patients with common comorbidities would thus be serving a highly select and atypical patient population. In the separate report on the demonstration design, we recommend excluding such programs from the demonstration.

Several commenting organizations said that it was extremely important for case management entities to develop a strong network of medical, nonmedical, and community-based resources. These organizations realize that the patient populations they serve often have multiple, complex, and interacting medical and social problems, and that the best chance of reducing the need for hospital admissions and other expensive medical care is to intervene proactively with less expensive community-based services. Several of the programs we studied also mentioned the important role that community services play in the care plans they developed to overcome patients' barriers to improved health. Others have also stressed the key role of community resource organizations in case management (HMO Work Group on Case Management 1999).

In addition to the general statements on care coordination providers given above, commenting organizations also made reference to two specific organizational issues: (1) whether a care coordination program should be part of an integrated delivery system, and (2) whether interdisciplinary teams enhance the care coordination process.

a. Integrated Delivery Systems

We received two comments claiming that integrated delivery systems have a unique ability to facilitate communication and collaboration. Not surprisingly, both comments were from care coordination programs operating inside integrated delivery systems. The first program suggested that successful care coordination programs should incorporate clinical care coordination into the physician-patient relationship. They believed that this type of relationship could be accomplished most successfully in vertically integrated, provider-oriented health systems because it is easier to achieve collaboration among providers in this setting.

The second program suggested that it is critical for care coordination programs to involve all providers and sites to provide coordinated, integrated, and comprehensive care. They believed that this goal would be most successfully achieved in provider organizations working in an integrated delivery system, because in this setting providers could be given strong incentives to follow best practices guidelines and could be made to feel part of the process, thus increasing participation and compliance. This commenter believed that care coordination programs developed by managed care organizations, disease management companies, or other commercial vendors would be unlikely to fulfill these key requirements for success.

Although care coordination may be more easily achieved in an integrated delivery system in which the organization has a high degree of control over its providers and the structure of its care delivery processes, we found examples of successful programs in our best practices study that were *not* part of an integrated delivery system. Thus, such a restriction does not seem to be necessary or wise.

b. Interdisciplinary Teams

The most common type of organizational feature called for by commenting organizations was the creation of interdisciplinary teams that had a mix of providers and that worked effectively together. Suggestions for the composition of these teams varied. For example, one organization recommended that the interdisciplinary team include a geriatrician and a nurse practitioner, registered nurse or social worker care team, in addition to the patient's primary care physician. A state Medicaid agency recommended including a gerontologist, nurse practitioner, pharmacist, nutritionist, physical therapist, and mental health specialist on the interdisciplinary team.

Many of the case management programs we studied tried to promote multidisciplinary input into the care coordination process--a sort of virtual team. Only the team program models, however, had actual teams physically located in one place. These models were based in large multispecialty clinics or in hospital-sponsored clinics, where both physicians and other team members (such as nurses and pharmacists) were employees of the organizations. Such models could be difficult to implement in fee-for-service Medicare where most primary care physicians are in private, office-based practice.

2. Care Coordinator's Role

The aspect of care coordination programs most frequently commented on was the role of the care coordinator. Organizations commented on the tasks to be performed by care coordinators, how they should interact with other care providers, and what types of providers are qualified to be care coordinators.

a. Care Coordinator Responsibilities

Four organizations commented on the types of services that care coordinators should provide. There was general agreement that they should provide a comprehensive set of services encompassing clinical, psychological, and social aspects of care for the chronically ill. One program said that care coordinators need to be seen as advocates for patients and agents for physicians, and that programs that cannot accomplish this "will not facilitate the level of fluid communication required for desired outcomes." However, another organization downplayed the role of care coordinators, saying that, although they play a critical role in delivering care to the most needy patients and in coordinating care among providers, they are merely one component of a comprehensive approach that should focus on the physician as leader.

There was some disagreement over whether care coordinators should be allowed to authorize services. Two organizations stated that care coordinators should be intimately involved in patients' care, including not only coordinating care and educating patients, but authorizing services as well. They believed that giving the care coordinator authority to both approve and coordinate services for the program's patients would ensure appropriate utilization of services and result in significant and immediate cost savings.

Another organization, however, suggested that, to avoid a conflict of interest, care coordination and benefit authorization should occur in separate departments. They believed that, in proactive community care coordination programs, it is difficult to combine care coordination with the authorization of benefits or benefits management because it is important to be focused on the clinical management of the patient and the development of a therapeutic partnership with the patient and the provider. They felt that this would be difficult if the care coordinator was also authorizing benefits.

Although the issue of whether to separate care coordination and benefits authorization is important to programs based in commercial health plans or managed care organizations, it seems less relevant to the Medicare fee-for-service sector. As described in our design report, we recommend that demonstration programs operate within current traditional Medicare benefits. The intent of the demonstration is not to test a new or different package of benefits. In the demonstration, responsibility for determination of Medicare coverage will continue to lie with HCFA's fiscal intermediaries and carriers.

b. Care Coordinator's Relationship with Other Providers

Commenting organizations all agreed that the care coordinator should work to coordinate care between all providers, not only physicians and hospitals but also home health agencies, physical and occupational therapists, laboratory vendors, durable medical equipment vendors, infusion therapy vendors, and pharmacies. In addition to their relationship with these providers, a high level of involvement with physicians was considered paramount for the care coordinator's effectiveness. One organization, however, warned that coordinated care should not be seen as merely a sophisticated case management model operating independently or separately from day-to-day care.

Rather, they saw it as a model in which care coordinators, while playing a crucial role in delivering care to the neediest patients and coordinating among providers, are just one component of a fully comprehensive approach.

This caveat relates to a comment made by a patient advocacy group that warned that adding another practitioner, such as a care coordinator, to the patient's roster of providers in fee-for-service may further fragment the delivery of covered services and thereby confuse beneficiaries. This group questioned how care coordinators would relate to those who provide care coordination in the current system (for example, hospital discharge planners and care coordinators employed by home health agencies and other post-acute care providers). Although this group agrees with the basic role and functions described for care managers by other commenting organizations, they say that care coordination programs must carefully define the limits of their scope of services so that both beneficiaries and other providers can see their value and understand how these services can best be utilized.

The patient advocacy group noted that, traditionally, the physician has been, and should ideally continue to be, the coordinator of patient care. At the same time, they acknowledge that the complexity of health care today, plus a seeming lack of interest on the part of physicians, has forced other types of providers to step in to fulfill the role of care coordinator. This group calls for additional physician training and financial incentives, to make physicians more accepting of the care coordinator role.

This patient advocacy group and another commercial vendor also felt that the degree of clinical and financial independence in the care coordination process are important considerations for the beneficiary. They believe that a care coordinator who is not independent from the hospital, home health agency, or skilled nursing facility may have a compromised ability to make assessments and care arrangements fully in the beneficiary's interest.

All the programs studied in the best practices report clearly viewed themselves as advocates for patients, providing services to address patients' barriers to improved health. However, financial and organizational incentives do hold the potential for causing care coordination programs to behave in a "perverse" fashion. In our design report, we suggest that payment incentives be linked to both Medicare savings and improvements in patient outcomes.

c. Qualifications of Care Coordinators

Six programs submitted comments on the skill level of care coordinators and the amount of training they need. Most of these programs attributed their success to the use of advanced practice nurses or nurse practitioners as team leaders. In general, there were no claims that either registered nurses or other lesser trained providers (for example, LPNs) could be used exclusively to provide high quality care coordination services.

One health plan-based program attributed its success to the use of advanced practice nurses with master's degrees. This program said that such nurses have a good understanding of all aspects of care and the role of specialist physicians, so they know when to discuss the possibility of consultations with another physician, a social worker, or a physical therapist with the primary care physician. They suggested that to build a strong partnership with physicians, the care coordinator should function at a high clinical level.

3. Physician's Role

Seven organizations commented on the level of physician involvement in care coordination. Although all agreed that active physician participation is critical, there was a range of expectations as to what this activity would include. One program in an academic medical center stated that physicians should be central to the decision-making process regarding specific interventions that should be delivered to the patient. This program felt that other programs that focus on case management and bypass the physician are destined to fail. At least one other program, a commercial vendor led by physicians, echoed this opinion, saying that, in a Medicare fee-for-service setting, it is critical to have a physician-led team approach to care.

Other commenters stressed the need for the care coordination program to communicate with physicians in a timely manner and keep clinical decision making in the hands of the physician. They agreed that programs should be designed to extend and enhance what physicians already provide through routine office visits, in order to get physicians to participate more fully (making it easier for programs to obtain referrals and to get physician adherence to guidelines and protocols).

4. Patient and Family Involvement

Few of the comments submitted by organizations dealt with the role of patients and families. Although two organizations mentioned that they viewed the patient as an untapped resource, and they tried to make patients active partners in their care, neither gave specific details as to how they believed patients and families should best be engaged.

One commenter believed that care coordinators work with enrollees and their families to implement the care plan. For example, this commenter finds the issue of advance directives to be useful for engaging the patient, family, and physician in a discussion about the status and progression of the patient’s medical condition and how this condition affects the patient’s quality of life. This commenter also believes that, whenever appropriate, the case management model should take the care to the patient’s living setting.

B. TOOLS AND SERVICES THAT ADD VALUE TO CARE MANAGEMENT

Commenting organizations highlighted several tools and strategies that they believed demonstration programs should use.

1. Risk Stratification

Four commenters addressed the issues of patient identification and risk stratification. One respondent suggested that care coordination programs should be able to proactively identify patients by tracking administrative and claims data for patterns of care or the absence of patterns of care (for example, the absence of claims for visits to a primary care physician for someone previously diagnosed with diabetes). They believe that better clinical outcomes and cost savings can be achieved if high-risk patients are identified proactively rather than waiting to identify patients from retrospective claims data (such as after a hospitalization has occurred).

Another commenter advocated a much broader approach to patient identification and risk stratification by suggesting that the care coordination entity should perform a risk assessment of each Medicare enrollee identified by HCFA as being moderate to high risk. This focused, risk-assessment approach would allow resources to be targeted to enrollees who present the highest risk. This commenter believed that this initial screening could be completed utilizing claims data or other information.

There was general agreement that risk stratification is an important tool for any care coordination program. Respondents agreed that care coordination is not appropriate for all patients and that resources would be used most effectively if programs focused on the needs of moderate- and high-risk patients. However, there were slight differences of opinion on the goals of the risk stratification process. Seven commenters believed that programs should incorporate clinical practice guidelines or other evidence from published literature.

2. Evidence-Based Medicine

Seven organizations said that their programs incorporated either clinical practice guidelines or other evidence from published literature. All but one were disease management programs. Several of these commenters also offered specific examples of why guidelines were important in care coordination. All the disease management programs studied in the best practices report relied extensively on national guidelines for their specific diseases.

A disease management program at a large academic medical center suggested that clinical care guidelines need to be up-to-date and on the cutting edge and that new advances in medicine should be incorporated quickly into care protocols. They cited the fact that clinical practice guidelines developed by specialty organizations are updated only approximately every five years. Even protocols based on these national guidelines need to be supplemented with new findings from the literature, to keep them current with advances in technology.

Another commenter, a commercial disease management company, said that their guidelines help standardize their patient protocol and ensure consistent delivery by the care manager. One commercial vendor said that the published literature provided the science, and that their mission was to implement or translate these findings for a general patient population.

3. Information Systems

Information systems can be an important component of a care coordination program. Although many commenters touted the superiority of their own proprietary systems, few provided specific examples of what care coordination information systems should include. Three commenters stated that information systems are a vital component of their programs. One said that care coordination programs should mandate the use of an electronic medical record that includes decision support capabilities. They felt that such a record system would ensure implementation of applicable evidence-based guidelines, comprehensive data collection, and outcomes reporting. Another said, specifically, that the information system should be an essential component of the care team's process, as well as be accessible to the physician from his or her office. One state-based program still under development said that its information system will connect its care coordination team, primary care physicians, and other caregivers. This program's information system will integrate an existing, automated client assessment system, client financial eligibility information system, and e-mail communication system with a new information and referral system, automated plan of care document, automated screening tool, automated monitoring and client contact reporting system, and automated client report.

We saw a wide range of reliance on information systems in the programs we studied. Some of the programs, particularly the disease management programs, had sophisticated systems. Other programs, however, did not seem to place great emphasis on their information systems. As with other variable features of the care coordination programs, the role played by the information system seemed to be a function of the characteristics and needs of the patients served by the program.

4. Using Technology to Reach Chronically Ill Patients

Commenting organizations recognized the logistic difficulties of providing care coordination services to rural and other isolated populations. Telephonic monitoring was most often suggested as a means to deliver care coordination services to this group of patients. Another suggestion was to use the Internet or an Intranet site. These technologic tools would be used in conjunction with in-home services provided by local home health agencies subcontracted to the care coordination entity.

The care coordination program would train, monitor, and manage the activities of the home care agencies, to ensure the quality of care. A major concern of commenting organizations about the use of telephonic care coordination was that, currently, no reimbursement is available under Medicare for technology-based programs. HCFA would need to address this issue, along with other reimbursement changes.

One commentator, a university research program in telephonic health care, provided a forecast of how telephonic case management would transform health care in the 21st century. They foresee telephonic case management resulting in cost saving in three areas: (1) decreased hospitalizations, (2) decreased office visits and related services, and (3) longer-term reduction in health services of all types due to reductions in the frequency and severity of the complications of chronic illness. Furthermore, they believe that the use of technology will lead health care to become more continuous, based less on physical institutions, such as physicians' offices or hospitals, and more centered on where the patient is.

Some of the disease management programs we studied, none of them rural, were using innovative technology. One program used an interactive voice response telephone system for patients to report their daily vital signs and symptoms. This same program was also experimenting with a web page for patients to enter data. Another disease management program provided automated telephonic health education, and a third relied on an ambulatory monitor to detect asymptomatic episodes of cardiac ischemia (insufficient blood flow). One of the rural programs was considering using video telephonic technology but had not yet started to do so.

C. FINANCING AND INCENTIVES

The greatest number of comments submitted concerned the difficulties with financing care coordination services in a Medicare fee-for-service setting and the need to provide appropriate incentives to involved providers of care. These problems were summarized by one commenter, who said:

> In the Medicare fee-for-service arena, there is no incentive to manage patient care efficiently. While providers are committed to offering their patients the best available medical care, they generally are not reimbursed for preventive care or for patient monitoring outside of the physician's office. At the same time, there is no existing incentive to minimize expenditures. Physicians have little financial reason to minimize the number of office visits, emergency room visits, or hospital admissions. However, we believe that creating financial risk sharing arrangements is often key to motivating program participants and realizing the full scope of potential improvements in outcomes.

These sentiments were echoed by many other organizations, some providing very different types of services in different settings, but who would all fit together under the umbrella of care coordination in Medicare fee-for-service.

1. Current Fee-For-Service System

Many commenting organizations alleged that the current fee-for-service system creates disincentives for hospitals and physicians to participate in or develop care coordination programs because reductions in hospitalization lead to lost revenues. One commenter expressed concern that provider reimbursement in the Medicare fee-for-service system pays more for discontinuity and for performing procedures, even though chronic illness requires continuity, dependability, counseling, symptom management, and family support.

Instead, commenting organizations called for a new reimbursement scheme to encourage physician participation in care coordination and to reward hospitals and health systems for lost revenues resulting from efficient coordination of care. Commenters said that the demonstration should align the incentives of providers, the care coordination entity, beneficiaries, and HCFA.

Two commenter expressed the need to promote to beneficiaries how care coordination programs can benefit them. They suggested that it would be important for beneficiaries to see such programs as an enhancement of their Medicare fee-for-service benefit package that would help them improve their health and the quality of their health care. Both commenters saw access to long-term support not only for education upon enrollment, but for continuous reinforcement, as major incentives for patients to enroll in care coordination programs.

2. Suggested Features of a New Payment System

A major component of the coordinated care demonstration project will be the design of a payment mechanism that will work within the Medicare fee-for-service system. Because the majority of care coordination programs now in existence operate in a managed care environment, it will be a challenge to find the combination of reimbursement and incentives that will allow HCFA to achieve its dual objectives of cost savings to Medicare and improvement of health outcomes for beneficiaries.

a. Payment and Incentives for Care Coordination Entities

The majority of public comments recommended that HCFA create a payment methodology that rewards the care coordination entity for performing according to objectives. These commenters believe that this task could be accomplished by aligning the program's objectives with HCFA's through risk-sharing arrangements. Most of these commenters said that these risk-bearing arrangements should pay a fixed fee for out-of-pocket costs and allocated overhead of the model and include a sharing of the confirmed savings to the Medicare system.

For example, one commercial commenter suggested that a fee-plus-incentive model should be considered for the care coordination entity because this approach would provide incentives for all providers to render the best quality of care, resulting in reduced hospitalizations, a primary driver of Medicare costs. This vendor suggested that HCFA use claims data to determine the anticipated costs of caring for current patients under the traditional fee-for-service system and to develop a unit of payment. The resulting monthly costs would be adjusted for case mix and used as the basis for the benchmark against which fees would be established and the risk amount set. The care coordination entity would receive a monthly payment based on the number of patients enrolled in the program and adjusted for case-mix severity. This unit of payment would be used to pay for all care coordination services provided, to pay physicians, and to possibly pay for certain pharmaceutical costs. This vendor also suggested that HCFA should cover additional benefits (for example, long-term care benefits, pharmacy) if they are shown to be cost-effective.

b. Payment and Incentives for Physicians and Beneficiaries

Three organizations commented specifically on payment and incentives for physicians. Two raised the possibility of additional fee-for-service payments to physicians for the additional work of participating in a care coordination program (such as by modifying existing evaluation and management CPT codes, or by creating new service codes). Both organizations ultimately believed however, that placing physicians at financial risk for some or all of the costs of medical care was the best way of aligning physician incentives with, and maximizing physician commitment to, the goals of care coordination. One organization mentioned non-financial incentives. This commenter said that physicians may be resistant to programs for disease state management because they feel that these programs cannot improve on the care they already provide and that it will lead to increased paperwork and inefficiency. They thought that physicians would cooperate with these programs, however, if they saw evidence of improved clinical, quality of life, and economic outcomes while also making the process of patient care easier. There were some general statements among commenters that most patients enjoy the added attention and improved health resulting from participating in a care coordination program, but no organizations discussed providing any specific incentives to beneficiaries.

c. Linking Reimbursement with Outcomes

Many commenters stressed that reimbursement should be aligned with outcomes but suggested different ways to accomplish this goal. Although most commenters recommended this approach to financing, usually they included only the reduction of Medicare programs costs as the desired outcome. A few commenters suggested additional types of outcomes that could be measured. For example, one commenter believed that care coordination services should be reimbursed at higher levels if they exceed expectations and certain quality benchmarks. Another commenter suggested that demonstration programs be required to have a written quality assessment process to guide and direct the development and implementation of the coordinated care or case management services. One commenter suggested that, in addition to linking reimbursement with quality care and cost savings, reimbursement could be linked to patient satisfaction.

Our design report recommends a payment system that provides incentives to programs, both to reduce Medicare expenditures and to improve quality of care. Since the report advocates a randomized design for the demonstration, Medicare cost savings would be calculated from the treatment-control comparison.

D. PATIENT ENROLLMENT

Patient enrollment will be another major issue in the design of the demonstration. Care coordination programs have often found that achieving enrollment targets has been more difficult than expected. One commercial vendor commented on this issue, saying that the way in which patients are enrolled into a disease management program can make a big difference in the program's outcomes. This commenter stated that when their program relied on active enrollment, in which the patient's physician must refer the patient or the patient volunteers, they were able to get only about a 30 percent participation rate in their eligible patient population. However, if they used passive enrollment, in which individuals who meet the target criteria are automatically enrolled unless specifically asking not to be, they were able to achieve approximately 98 percent participation. Another vendor also suggested that HCFA should implement a passive or "opt-out" approach to patient enrollment. This commenter believed that this approach would achieve higher participation and significant cost savings, and reduce administrative program costs.

For the demonstration design report, we discussed the pros and cons of the two enrollment approaches. Although passive enrollment can lead to higher participation rates, it may lower impacts because the enrolled patients may be less motivated to comply with self-management protocols.

Related to the issue of patient enrollment is the ability of the care coordination program to retain the patient in its program. One commenter suggested that the reason insurers and governments have not invested more heavily in care coordination programs is that commercially insured patients and even patients enrolled in Medicare HMOs change their insurance coverage frequently, causing insurers who invest in the care coordination programs to lose their enrollees before they see a return on their investment in the program. A commercial vendor agreed that the problem with providing disease management for patients in Medicare HMOs is that there is no patient lock-in--that is, patients can disenroll from the Medicare HMO at will.

We acknowledge that voluntary disenrollment from care coordination programs by beneficiaries may be a problem for demonstration programs. However, we recommend that programs not be allowed to "lock in" enrollees. We believe that enrollee lock-in is contrary to the fundamental philosophy of the Medicare fee-for-service program and may possibly discourage patients from enrolling in demonstration programs. Effective care coordination programs that are able to convince beneficiaries of their value should not need to impose this type of restriction on their enrollees.

E. DISEASES AND CONDITIONS FOR CARE COORDINATION

One commentator pointed out that care coordination programs have, not surprisingly, focused on conditions where improved management can lead to short-term payoffs, such as congestive heart failure or chronic obstructive pulmonary disease. Improved control of other conditions--such as hypertension, elevated cholesterol, obesity, smoking, and osteoporosis--often do not lead to decreased health care utilization until years or decades later. These conditions have generally received less attention from managed care organizations and the commercial care coordination vendors that market to them, perhaps because many commercial and managed care plan enrollees often do not stay in plans long enough for the plans to see the benefits of addressing these conditions.[2] We agree with this comment, but HCFA, which *is* interested in long-term outcomes of Medicare beneficiaries, has already funded separate research in such areas as the Dean Ornish program and healthy aging. Thus, we see the Medicare Coordinated Care Project, which focuses on those who are already ill or at high risk in the short term for adverse events, as complementing these other efforts, which target those who are not yet ill but for whom improvements in lifestyle and behavior may lead to decreased morbidity and health services use in the long run.

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[2] Disease management programs sponsored by pharmaceutical companies are an exception. Pharmaceutical companies manufacture medications for these conditions and are naturally interested in increased attention to these conditions.

APPENDIX B

PUBLICITY EFFORTS FOR BEST PRACTICES SOLICITATION

TABLE B.1

PUBLICITY EFFORTS FOR BEST PRACTICES SOLICITATION

Journals in Which a Notice was Published[1]
Annals of Internal Medicine
Business and Health
Eli's Home Health
Journal of the American Geriatrics Society
Journal of the American Medical Association
Journal of Quality of Improvement
Managed Care Magazine
E-Mail Lists, Listservs, or Electronic Bulletin Boards on Which a Notice was Broadcast or Posted
American Association of Health Plans (AAHP) Website
American Academy of Home Care Physicians Website
American Association of Homes and Services for the Aging (AAHSA) Website
American College of Physicians-American Society of Internal Medicine (ACP-ASIM) Bulletin Board
American Group Medical Association (AMGA) Bulletin Board
Case Management Society of America Website, CMSA
CASEMGR, listserv for case managers
DiseaseMgt, disease management forum,
FAMILY-L, academic discussion list for family medicine
FINAN-HC, health care financing and administration list
Gerinet, discussion list for geriatrics and gerontology
HealthMgt, discussion list for health care management personnel
HSR-L, Health Services Research List
NAPCRG-L, North American Primary Care Research Group List
Organizations to Which a Letter about Solicitation Was Sent
American Diabetes Association National Office
Case Management Society of America
National Association for Home Care
National Chronic Care Consortium
American Association of Retired Persons (AARP)
National Rural Health Association

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[1] We approached many journals, but these were the only ones willing to publish the notice as a public service announcement. As mentioned in the report, HCFA also published a notice in the *Federal Register*.

TABLE B.1 *(continued)*

American Hospital Association (AHA) Chicago Headquarters (CH)
National Association for the Support of Long Term Care
American Association of Homes and Services for the Aging (AAHSA)
National Institute on Aging National Institutes of Health
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) National Institutes of Health
National Institute of Mental Health National Institutes of Health
Administration on Aging
American Association of Health Plans
American Public Health Association (APHA)
American College of Physicians Headquarters
American College of Physicians Washington Office
American Geriatrics Society
American Academy of Family Physicians
National Gerontological Nursing Association (NGNA)
American Academy of Nursing
Gerontological Society of America
The Robert Wood Johnson Foundation P.O. Box 2316
The Commonwealth Fund
Medical Group Management Association
The National Association of Social Workers (NASW)
American Geriatrics Society
Alzheimer's Association
Behavioral and Social Research Program National Institute on Aging, NIH
Center for Primary Care Research Agency for Health Care Policy & Research Executive Office Center
National Heart, Lung, Blood Institute
American Heart Association
American Nurses Association
Alzheimer's Association National Office
American Heart Association National Center

TABLE B.1 *(continued)*

The John A. Hartford Foundation
Arizona Rural Managed Care Center Rural Health Office University of Arizona
Maine Rural Managed Care Demonstration Center Muskie Institute Research Program University of Southern Maine
Oklahoma Rural Managed Care Demonstration Center College of Public Health, Health Sciences Center University of Oklahoma
Program of Rural Health Demonstration Activities Preventive and Social Medicine, College of Medicine University of Nebraska Medical Center
Office of Rural Health School of Medicine and Biomedical Sciences State University of New York, Buffalo
Cecil G. Sheps Center for Health Services Research University of North Carolina
Institute for Health Services Research School of Public Health University of Minnesota
Center for Health Policy Research
Department of Health Services, SC-37 School of Public Health and Community Medicine University of Washington
West Virginia Rural Managed Care Demonstration Center Office of Rural Health, Robert C. Byrd Health Sciences Center West Virginia University
Maine Rural Health Research Center Edmund S. Muskie Institute of Public Affairs
University of Minnesota Rural Health Research Center Institute for Health Services Research School of Public Health
New York Rural Health Research Center Office of Rural Health, Department of Family Medicine State University of New York at Buffalo Beck Hall, South Campus
North Dakota Rural Health Research Center The Center for Rural Health The University of North Dakota, School of Medicine
WAMI Rural Health Research Center Department of Family Medicine University of Washington
Center for Family Research in Rural Mental Health Department of Sociology

TABLE B.1 *(continued)*

Center for Rural Mental Health Care Research Department of Psychiatry and Behavioral Sciences University of Arkansas for Medical Science
Mental Health Services Research Center University of Washington
Southeastern Rural Mental Health Research Center Madison House
Federal Office of Rural Health Policy
Florida Rural Health Research Center Institute for Health Policy Research University of Florida
Center on Aging and Health in Rural America Pennsylvania State University
Center for Research on Older Rural Populations Preventive Medicine Department University of Iowa
Center for Rural Health and Aging University of Florida J. Hillis Miller Health Science Center
Exploratory Center for Rural Health and Aging Cecil G. Sheps Center for Health Services Research University of North Carolina at Chapel Hill
Department of Health and Human Services Office of Assistant Secretary for Planning and Evaluation Disability, Aging, and Long Term Care Policy
Healthcare Demand & Disease Management National Health Information
The National Association of Professional Geriatric Care Managers

APPENDIX C

ELIGIBLE BUT NOT INTERVIEWED PROGRAMS, AND INTERVIEWED PROGRAMS

TABLE C.1

LIST OF ELIGIBLE BUT NOT INTERVIEWED PROGRAMS

Program Name	**Organization**	**Disease-Specific**
Community Medical Alliance	Neighborhood Health Plan, Boston, MA (Master 1998)	Severe Physical Disability and AIDS
Care Management of the Frail Older Adult	Crozer-Keystone Health System, Chester, PA	No
Community Case Management Services	Bridgeport Hospital, Bridgeport, CT	No
Coordinated Care Solutions, Inc.	Coordinated Care Solutions, Inc., Coral Springs, FL	No
Nursing Home Care Management	Fairview Partners, Minneapolis, MN	No
Health Enhancement Project	Group Health Cooperative of Puget Sound, Seattle, WA (Leveille et al. 1998)	No
Ventana Health Systems	Lifemark Corporation, Phoenix, AZ	No
Integrated Care and Case Management Project	Università Cattolica del Sacro Cuore, Rome (Bernabei et al. 1998)	No
CNS Directed Case Management Demonstration Project	Sioux Valley Hospital Center for Case Management, Sioux Falls, SD (Gibson, et al. 1994)	No
Sutter Chronic Care Program	Sutter Health System, Rancho Cordova, CA	No
Evercare	United Health Group, Minnetonka, MN	No
Partnership Health	University of Michigan Medical School, Ann Arbor, MI, and Ford Motor Company, Dearborn, MI	No
Nurse Case Management	Via Christi Regional Medical Center, St. Joseph Campus, Wichita, KS (Swindle et al. 1994)	No
Quality Oncology	American Disease Management, Inc., McLean, VA	Cancer
Respiratory Wellness Programs	AirLogix, Inc., Dallas, TX	Asthma and COPD
Diabetes Education	Alacare Home Health Services, Inc., Birmingham, AL	Diabetes
Cardiomyopathy and Heart Failure Program	Boston Medical Center	CHF
MULTIFIT Comprehensive Management System for Heart Failure	Stanford University School of Medicine (West et al. 1997)	CHF
CarePatterns Programs for Disease Management	Caremark, Inc., Northbrook, IL	Diabetes, Asthma, CHF, Arthritis, Peptic Ulcer, Hemophilia, Hepatitis C, Multiple Sclerosis, RSV, Human Growth Hormone Deficiency
Evanston Congestive Heart Failure Program	Evanston Hospital, Evanston, IL (McCarthy 1997)	CHF
Nurse led Clinics in Primary Care for Secondary Prevention in Coronary Heart Disease	Foresterhill Health Centre, Aberdeen, UK(Campbell et al. 1998)	CHD
Mercy Franciscan Asthmacare	Franciscan Hospital-Mt. Airy Campus, Cincinnati, OH	Asthma

TABLE C.1 *(continued)*

Program Name	**Organization**	**Disease-Specific**
Healthtrac Programs	Healthtrac Inc., Menlo Park, CA	Diabetes, Asthma, Arthritis, HTN, COPD, chronic back pain, Parkinson’s, stroke, CHD
Multidisciplinary Intervention to Prevent the Readmission of Elderly Patients with CHF	Jewish Hospital of St. Louis at Washington University (Rich et al. 1995)	CHF
Garfield Palliative Care Project	Southern California Kaiser Permanente, Downey, CA	Terminal illness
Malmo University Hospital Heart Failure Program	Malmo University Hospital, Malmo, Sweden (Cline et al. 1998)	CHF
Heart Institute Risk Reduction Programs	Mercy Health Care of Sacramento, Sacramento, CA	Diabetes, CHF, HTN, CHD
Community Case Management	Mercy Health Center, Dubuque, IA	CHF, COPD, stroke, diabetes, CHD
CHF Chronic Care Community Case Management	Mercy Health Partners of Southwestern Ohio, Cincinnati, OH	CHF
Shorefront Jewish Geriatric Center	Metropolitan Jewish Health System, Brooklyn, NY	CHF
Senior Health Connections	Northeast Ohio Neighborhood Health Services, Inc., Cleveland, OH (Anderson et al. 1999)	No
Respi-Care	Norwalk Hospital, Norwalk, CT (Haggerty et al. 1991)	COPD
CHF Disease Management Program	NYLCare Health Plans of New York, Inc., New York, NY (Roglieri et al. 1997)	CHF
Disease Management for Congestive Heart Failure	ScrippsHealth Chronic Care Clinic, La Jolla, CA (Brass-Mynderse 1996)	CHF
Service Credit Banking Project (Sentara Volunteer Caregiving) Asthma Program	Sentara Life Care Corporation, Norfolk, VA	Asthma
Sharp Pulmonary Rehabilitation Program	Sharp Memorial Hospital, San Diego, CA	COPD
Q Program	Spectra Renal Management, Lexington, MA	ESRD
Congestive Heart Failure Follow-up Program	St. John’s/Hammons Heart Institute, Springfield, MO	CHF
Intensive Home-Care Surveillance for Elderly CHF Patients	Tel-Aviv University, Sackler School of Medicine, Tel Aviv, Israel (Kornowski et al. 1995)	CHF
Comprehensive Heart Failure Management	University of California at Los Angeles School of Medicine (Fonarow et al. 1997)	CHF
Comprehensive Long-Term Management Program for Asthma	University of Tennessee, Memphis, TN (Kelso et al. 1996)	Asthma
Interactive Home Monitoring Program for CHF	Univ. of California at San Francisco and San Francisco VA Medical Center (Shah et al. 1998)	CHF
Vida Cancer Care Management Program	Vida Healthcare, Inc., Eden Prairie, MN	Cancer

NOTE:
CHF = congestive heart failure
CHD = coronary heart disease
COPD = chronic obstructive pulmonary disease
HTN = hypertension
ESRD = end-stage renal disease
RSV = respiratory syncitial virus

Family Practice Residency Program, Medical Center of Central Georgia, Macon, GA, a non-disease specific program for nursing home residents only, also had strong pre-post evidence for reduction in hospitalizations. Early in the study we had excluded programs that served nursing home residents only, thus excluding a few programs. Much later in the study we did decide to include such programs, but by that point it was too late to study any of the originally excluded programs in any depth.

TABLE C.2

INTERVIEWED PROGRAMS

Disease Management Programs

Crozer-Keystone Health Systems Heart Success Program, Chester, PA

Provider Services Group, Inc. Health Advocacy Program, Minneapolis, MN

Blue Cross/Blue Shield of Massachusetts CHF Program, North Quincy, MA

Lifemasters Supported SelfCare CHF Program, San Francisco, CA

Cardiac Solutions, Inc. Heart Failure Management Program, Buffalo Grove, IL

Queen Elizabeth Hospital/University of Adelaide Home-Based Intervention for CHF, Woodville, South Australia (Stewart et al. 1999)

Northern California Kaiser-Permanente Santa Rosa Office HIV Interdisciplinary Team, Santa Rosa, CA (Le et al. 1998)

FutureHealth Corp. Integrated Risk Management Program, Timonium, MD

Diabetes Treatment Centers of America Diabetes NetCare Program, Nashville, TN (Rubin et al. 1998)

Interactive Heart Management Corp. Cardiovascular Disease Management Program, Lawrence Harbor, NJ

University of Pennsylvania Health System's Programs in Health and Disease Management, Philadelphia, PA

Case Management Programs

Winchester Hospital Senior Health Partnership, Winchester, MA

University of Pennsylvania School of Nursing Comprehensive Discharge Planning Program, Philadelphia, PA (Naylor et al. 1999)

North Iowa Mercy Health Center Community Case Management, Mason City, IA

Carondelet Health Network, Tucson, AZ (Burns and Santos 1996; Reczak et al. 1999)

United Mine Workers of America Geriatric Care Program, Washington, DC (clinical sites in WV, KY, AL)

Anthem Blue Cross/Blue Shield of Connecticut, North Haven, CT

Sir Mortimer B. Davis Jewish General Hospital Nurse Case Management Program, Montreal, Canada (Gagnon et al. 1999)

Queen Elizabeth Hospital/University of Adelaide Home-Based Intervention, Woodville, South Australia (Stewart et al. 1998)

Status One Health Care Systems, Hopkinton, MA (Forman and Kelliher 1999)

Henry Ford Health System Geriatric Team Model, Detroit, MI (Whitelaw et al. 1999)

United Health Services System Case Management, Birmington, NY (Battaglini and Czerenda 1999)

Geriatric Medical Services of Providence Hospital, Washington, DC

Albany VA Medical Center Geriatric Evaluation and Management Unit, Albany, NY (Toseland et al. 1996)

Colorado Kaiser-Permanente Cooperative Health Care Clinics, Denver, CO (Beck et al. 1997)

Carle Clinic Geriatric Collaborative Practice, Urbana, IL (Schraeder et al. 1999)

Sharp Memorial Hospital Senior Health Center, San Diego, CA

NOTE: Two of these programs were later not included in the final group of programs for further study. One was a group clinic intervention and not a true care coordination program. The second was a consulting organization that did not provide services closely.

APPENDIX D

METHODS USED BY STUDY PROGRAMS TO IDENTIFY AND SCREEN PATIENTS

In this appendix, we review how case management and disease management programs identified potential program participants and enrolled them.

A. CASE MANAGEMENT PROGRAMS

1. Capitated Organizations

Capitated organizations have an incentive to identify the small proportion of high-risk patients "hidden" among their large population of community-dwelling members and to intervene *before* costly events occur. Four of the five programs based in health plans or at-risk provider organizations thus used a population-based screening approach to find these patients. They first screened new enrollees with questionnaires to find *potential* recipients of case management.[1] Those with "positive" questionnaires were then either enrolled and given their initial assessment or evaluated with an additional brief telephone interview to confirm their high-risk status before enrollment and full initial assessment. This staged approach of initial screening of new enrollees, followed by further assessment, is the one recommended by authorities on case management in the managed care setting (HMO Workgroup on Care Management 1996; and Case Management Society of America 1995). None of the programs were screening existing enrollees. Existing high-risk members usually were identified when they were hospitalized or referred from physicians, physicians' office staff, hospital discharge planners, and health plan precertification nurses. Two of the programs also had started using claims data, but not yet in any systematic or routine fashion. The one remaining health plan-based program did no screening, but instead relied exclusively on referrals, primarily from PCPs but occasionally from family and even neighbors. Some of the programs circulated explicit

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[1] One program screened with the Pra instrument (Boult et al. 1993), while another used the Pra and the SF-36 instrument. A third program used a 108-item instrument developed by Tufts-New England Medical Center. The fourth used a proprietary instrument sold by a commercial company.

criteria to referral sources (such as physicians' offices and hospital discharge planners), whereas others merely provided general guidelines or descriptions of the types of patients they sought.

2. Hospital-Based Programs

On the other hand, the two hospital-based programs (an academic medical center and a rural community hospital) did not engage in any type of population-based case-finding effort. Hospitals already have among their current population elderly patients at high risk for future hospitalizations. Not surprisingly, then, the two hospital-based programs identified potential program participants from among their elderly inpatients. The program in the academic medical center first considered elderly patients hospitalized for any of the 10 most common reasons for Medicare beneficiary hospitalization in 1992, then further assessed these patients for a number of additional criteria.[2] The rural hospital-based program considered all elderly inpatients hospitalized for three or more days, as well as accepting referrals for patients in the community from family members, doctors, and patients themselves. This program then performed additional, brief assessments to determine suitability for case management.

3. Outpatient Programs in Fee-for-Service Environments

The three outpatient programs operating in fee-for-service (FFS) environments also did no screening, but instead relied entirely on patient self-referrals, physician referrals, and word of mouth. The programs were essentially enhanced primary care practices, sponsored by hospital-based provider networks, that provided not only primary medical care, but also case management. One

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[2] These included criteria related to practical limitations, such as residence near the hospital and ability to speak English, and to risk for poor postdischarge outcomes: age 80 or over; inadequate support system; multiple, chronic health problems; depression; functional impairment; multiple recent hospitalizations; poor self-perceived health; and history of noncompliance. Only patients without practical limitations and at risk of poor outcomes were enrolled.

program was in an environment in which it was necessary to avoid the appearance of "raiding" patients from the practices of other area physicians (most of whom were specialists). This program located in an area with few specialist practices and discreetly marketed itself to seniors through community organizations, senior centers, or senior housing sites. It encouraged local physicians to refer patients whom the physicians found too complex to handle or for whom the physicians no longer wished to be primary care providers. The second program served elderly residents of the low-income housing unit in which it was located, in addition to residents of several nearby assisted-living facilities. Again, patient entry into the practice was voluntary. The third program was a demonstration program in a physician-hospital organization, in which case managers were introduced into the offices of primary care physicians. The case managers relied entirely on the doctors or their office staff to refer to them any existing or new patients that should be case managed.

4. Multispecialty Group Clinics with Mixed Capitated and Fee-for-Service Patients

Finally, the program in a large multispecialty group clinic varied its approach with patients' insurance coverage. For their capitated patients, they used the two-stage, population-based approach (mailed questionnaire,[3] followed by telephone assessment for those with "positive" questionnaires), whereas for their FFS patients they relied mainly on provider referrals.

Thus, the way programs found their patients was highly dependent on the programs' environment and reimbursement. The population-based, case-finding approach has the advantage of detecting high-risk persons to be helped *before* they experience costly, adverse events, but it was not practiced by organizations not bearing risk for medical costs. We speculate that such an approach might be difficult to implement when there is no defined list of "covered lives," when there

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[3] This 50-item questionnaire was based on the assessment form that the Social HMO demonstration sites used.

are multiple competing providers and risks to being perceived as "stealing" patients from other providers, and when there are few incentives to prevent hospitalizations. However, even the hospital-based programs, where patients are often identified only after they are already hospitalized, were at least apparently effective in keeping people from *additional* admissions.[4]

B. DISEASE MANAGEMENT PROGRAMS

To find patients, disease management programs also relied to varying degrees on referrals, hospitalizations, and ER visits, and on analysis of computerized health plan data. Approaches also seemed to vary by programs' sponsorship.

1. External Commercial Disease Management Vendors

The three commercial programs that contract with managed care organizations relied heavily on analysis of their client plans' computerized data, or "data mining," to find patients, especially in the early phases of contracts. Their computer algorithms searched through available databases, which were generally encounter, laboratory, and pharmacy, for specific ICD-9 codes, laboratory tests, and medications. One program also mentioned searching databases of Durable Medical Equipment. Besides identifying potential patients for program intervention, data mining produced other useful information: the programs could distinguish physicians or physician groups with the most patients with the disease and could therefore target those physicians for education efforts. One program claimed that its analysis of pharmacy data also allowed it to define comorbid conditions for many patients. The sensitivity and specificity of these algorithms is unclear. One of the programs, a diabetes program, claimed that its algorithm had a 2 percent error rate and could detect 90 percent

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[4] Actually, the low-process case management program with impacts discussed separately in section D of Chapter IV was also hospital-based, did no population screening (finding patients only among its inpatients), and had strong evidence of being able to reduce the need for readmissions.

of a health plan's diabetic enrollees. Another program, however, described a 70 percent false-positive rate; that is, of the patients identified through its algorithm, only 30 percent actually had the diagnosis. Because of the variable accuracy of the algorithms, all programs confirmed potential patients' diagnosis with physicians.

Besides data mining, these programs also found patients through referrals from providers and patient self-referrals. The programs all mounted an awareness or "roll-out" campaign when they first began operations with a new client health plan. Campaign activities targeted to health plan enrollees included notices or articles in health plan newsletters, inserts in the payroll envelopes of employees of large employer subscribers of the health plan, and presentations at such events as new member orientations or health fairs. Campaign activities targeted to providers included all providers who might encounter appropriate patients. Such providers include PCPs and specialists, physicians' office staff, ER physicians and staff, hospital ward staff, hospital discharge planners and social workers, and health plan utilization review/utilization management staff. Thus the programs placed notices in health plan staff newsletters and payroll envelopes, mailed information to the above groups, and made presentations to these groups. One of the programs also set up a Physician Advisory Committee of physicians belonging to the health plan's network.

2. Internally Developed Programs

Three programs that were developed within a health plan or provider-sponsored organization seemed to rely primarily on referrals or on hospitalizations and ER visits. Through mailings and meetings, these programs expended considerable effort in promulgating awareness of the program among affiliated physicians, their staff, and the staff of affiliated hospitals.

Because of the unique features of HIV, the HIV program had some distinct advantages in identifying its target population. HIV is determined through a blood test, and because all blood tests were performed by the health plan laboratory, all newly discovered HIV-positive persons were detected. Persons undergoing the test also received pre-test counseling through the program, so those who were later found to be HIV-positive had already established some connection with program staff. There is also a unique set of medications used to treat HIV, so computerized pharmacy data accurately identified additional HIV-positive members under treatment who had been tested outside the health plan. Finally, to encourage referrals, the program publicized its existence among providers.