

Issue Brief

The Primary Care Team: Cornerstone of a Chronic Care Network

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The foundation of the work of the National Chronic Care Consortium (NCCC) is the development of chronic care networks (CCNs). A CCN is a person-centered, systems-oriented approach to managing care across time, place, and profession using care integration, disability prevention, and managed care financing methods to serve a common group of people with chronic conditions. This integration does not require ownership of assets; it does, however, require a clear vision, innovative ideas, and new skills. For clients, CCNs provide better care and easier-to-use services. For networks, better care results in cumulative cost savings.

The NCCC promotes the use of primary care teams as the cornerstone of a CCN. The primary care team is composed of an array of providers and practitioners brought together through clear communication systems to meet the needs of the client. The NCCC's vision of primary care for people with chronic conditions is consonant with the themes and principles of primary care for healthy people but recognizes the greater complexity of providing services to those with chronic illnesses. Primary care should be comprehensive, accessible, financially responsible, and coordinated over time and place. The challenge of providing these services to the chronically ill is best met by interdisciplinary care teams with clear leadership, designed to provide medically effective and cost-appropriate care that reflects client and family preferences.

This issue brief explores issues of serving the chronically ill, the role of primary care teams within systems of care, and strategies for creating CCNs to better serve the chronically ill.

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Introduction: Chronic Care Networks

Since its inception, the NCCC has worked toward developing systems of care that better meet the needs of individuals with serious and disabling chronic conditions. People with chronic conditions deal daily with the problems, pain, inconveniences, and exacerbations of diabetes, heart disease, arthritis, asthma, stroke, Alzheimer's disease, HIV/AIDS, and other conditions. Many frail elders suffer from any combination of these conditions. When they access healthcare, they find systems of care that are disjointed, duplicative, and difficult to navigate.

The NCCC has been working toward operationalizing a vision for integrated chronic care that would

- Take a systems-oriented approach.
- Empower individuals.
- Engage providers, payers, and consumers.
- Provide a full continuum of services.
- Focus on preventing further disability.
- Take a long-term view.

The principles of the CCN vision are described briefly below.

Systems Orientation

A systems orientation requires horizontal and vertical integration. When this integration occurs, information relating to the outcomes and total cost of care is collected across all settings and professions and is communicated to care providers, management, and financial administrators.

Person-Centered

Person-centered decisionmaking means that a person with a chronic condition is involved in all decisions about the ongoing provision of care and in ensuring that all care is modified to meet his or her unique needs wherever possible. Person-centered decisionmaking includes taking into account the relationships between all major dimensions of a person's life at any given point in time as well as over time. It also means working within the context of family and community. Family caregivers and informal supports (such as neighbors,

church/synagogue, and friends) assume a central role in the health and well-being of people in the later stages of chronic conditions.

Trinocular View

Although people trained in long-term care, primary care, and acute care all bring strengths to the table, each views care through very different lenses. All three perspectives are critical to minimizing the accumulation of costs over time and across settings and to attaining quality outcomes; chronic care integration requires that those involved in the delivery of services to the chronically ill adopt a trinocular view.

Full Continuum of Services

A full continuum of primary, acute, transitional, and long-term care services must be available to any chronically ill person.

Disability-Prevention Orientation

Society's cure-oriented, crisis-driven approach to planning and treatment in healthcare has resulted in remarkable improvements in acute care and trauma care. It has also resulted in a focus on end-stage healthcare to such an extent that the cost effectiveness of primary care and disease and disability prevention is often ignored. Preventing, delaying, and minimizing the progression of disability are critical functions of cost and quality.

Longitudinal Approach

Purchasers, payers, and providers continually restrict their involvement in care to single events or circumstances or narrow windows of time. It is important to address the interrelated aspects of care over time in order to identify risk factors associated with preventing disability and optimizing quality of life.

Healthcare and Chronic Disease

The U.S. healthcare industry has traditionally considered the core of its work to be acute, episodic illnesses treated in institutional settings. In fact, “most of our current health care policies, institutions, and methods of reimbursement were created during an era when acute diseases were most prominent” (Pawlson 1994). Today, delivery systems are adapting to the growing needs and desires of individuals by including a broader array of services, settings, and providers. Technological advances and reimbursement schemes have moved much diagnosis and treatment to the ambulatory and home settings. The needs of an aging population have also created the demand for more appropriate community-based services to meet needs that have traditionally been seen as tangential to the healthcare system.

As managed care becomes a more prominent player in the healthcare arena and executives become cognizant of the fact that more than 70 percent of all medical costs result from chronic disease and disability (Hoffman et al 1996), the focus has begun to shift to the chronic diseases such as hypertension, Alzheimer’s, arthritis, diabetes, and congestive heart failure that afflict our nation and raise costs for businesses and government. Linking the variety of providers and services needed to effectively manage the care of individuals with chronic conditions is becoming increasingly important. Without a more effective healthcare system, the future is not bright: people with chronic diseases currently represent the fastest-growing and highest-cost segment of healthcare, and the relative importance of this population will grow well into the twenty-first century.

In recent years, more attention has been given to disease-management strategies to standardize care in the hope of controlling costs and improving outcomes. However, condition-specific disease-management programs may not hold as much promise as hoped, especially for those with multiple chronic conditions. Many of the existing collection of providers and practitioners are

ill-prepared to function in the more team-oriented environment needed to manage chronic conditions, especially without a fundamental transformation of current administration, financing, and delivery systems to a CCN structure. Although there has been a significant change in the distribution of healthcare dollars among existing healthcare institutions, our delivery systems continue to “treat problems in response to acute events and to manage care within the walls of provider institutions and the confines of established professions” (Bringewatt 1995). Delivery systems are fragmented and incapable of following individuals over time and across settings.

Changing from an Acute Care to a Chronic Care Environment

Although the financial incentives for establishing CCNs do not yet exist, if one assumes a long-range view and looks through the lenses of those with chronic diseases and disability, the only solution is to integrate care as a person’s condition evolves across time, place, and profession. In the past, the term “chronic care” was synonymous with long-term care, but the industry is coming to the realization that chronic care covers the spectrum of primary, acute, and long-term care services. Providers and healthcare organizations can no longer consider themselves participants in the business of healthcare without recognizing the cost and impact that individuals with chronic illness place on the system.

As a care delivery model, CCNs allow care to be delivered in the appropriate setting by the appropriate team of providers. Such an integration of services and providers could control the accumulation of costs over time and improve outcomes by delaying or preventing costly and progressively debilitating flareups of the chronic condition. The challenge of delivering care for people with chronic conditions is often best met by a primary care management team system with clear leadership designed to provide the most medically effective and cost-appropriate care. In fact, because

primary care is by definition the coordinated provision of healthcare services over time and across settings (Institute of Medicine 1996), the primary care team is truly the cornerstone of the CCN vision.

The principles of primary care for healthy people are identical to those for people with chronic illness; however, people with chronic illness and disability utilize a more complex array of acute, long-term care, and community-based services. An integrated system of care and an involved primary care team can provide the necessary structure to access and utilize these services more effectively.

Cost of Chronic Disease

The United States spends \$425 billion per year on direct medical costs and nearly \$660 billion per year on total direct and indirect costs for people with chronic conditions (Hoffman et al 1996). In 1995 nearly 100 million people living in the community had one or more chronic condition. With the aging of the population that number is expected to reach 148 million by 2020 (Hoffman et al 1996). The prevalence of chronic conditions will continue to spiral upward well into the twenty-first century, consuming the attention of Medicare, Medicaid, and private payers.

At the systems level these numbers are equally significant. According to a study of a large staff model health maintenance organization (HMO) using 1992 data, the cost of care for people with chronic conditions is at least twice that for people without chronic conditions. In fact, the study found that the existence of a chronic condition could increase a person's healthcare costs by anywhere between 80 percent and 300 percent (Fishman et al 1997). At issue here is whether the care provided to people with chronic conditions is effective, efficient, or optimal relative to outcomes for the money and resources expended. Preventing disability and managing chronic illness are the most significant factors for containing costs over time and across settings.

Although many healthcare organizations would prefer to believe otherwise, our healthcare system is driven by reimbursement mechanisms. The traditional fee-for-service reimbursement system

provided little financial incentive for coordinating care of people with chronic conditions. The bias of the U.S. health insurance industry over the years has been toward institutional settings and providers. This has created disincentives for providing care in less costly, more appropriate settings such as the home or a community-based setting. Providers have had no reason to be concerned about the number of services that the chronically ill sought and utilized or how these services were coordinated. Therefore the focus has not been on risk identification, prevention, or care coordination.

The recent wave of reimbursement arrangements based on risk—per-diem rates, diagnosis-based payments, and capitated payments—has introduced a new set of financial incentives into the healthcare marketplace. However, unless the payment mechanisms of the providers throughout the system are aligned, financial incentives will continue to create barriers to integrated care. Conflicts are evident; one segment of the system may vie for per-diem dollars while another works to maximize per-admission dollars, yet another strives to minimize utilization of services, and still another receives payment on a fee-for-service or per-unit basis. Often, especially for those with chronic conditions, necessary services such as transportation, care management, preventive services, and meals are neither linked to the delivery system nor part of the funding stream, even though their availability is as important to the health of the individual as a doctor visit. It is managed care miscast as “miserly third-party administrator” that has created a less than favorable public image and in some cases has led to limits on consumer access to services, created disincentives for serving high-risk populations, and discouraged coordination and continuity of care.

Transforming Primary Care

As health systems and managed care plans become increasingly aware of the implications of chronic illness for utilization of resources and cost of care (especially for the accumulation of costs over time), primary care will move beyond its current gatekeeper role. The role of primary care within a CCN is much broader and more encompassing—the primary care provider and team are responsible for managing a full array of acute, long-term care, and community-based services. Although the team members may not all be co-located, the team must share a common goal and a unified approach (Etzwiler 1994).

The Primary Care Team

As defined earlier, primary care is the coordinated provision of healthcare services over time and across the array of settings where services may be accessed. The provision of primary care to the chronically ill is not the exclusive domain of any single healthcare profession. In fact, primary care relies on key relationships between a multidisciplinary team of providers, including nurses, care coordinators, physicians, physician assistants, nurse practitioners, therapists, social workers, clients, families and caregivers, patient educators, and community resource providers. Additional services from ad hoc team members such as psychologists, pharmacists, nutritionists, and complementary care providers may also be necessary.

For people with chronic conditions, the primary care component is the essential constant for organizing the myriad of services that can benefit the individual. The primary care team serves as the integrated entry point into the larger system for clients and their families. So, for example, the primary care team for a person with diabetes might consist of a physician, a nurse practitioner, a nutritionist, a diabetes educator, and a pharmacist.

Goals of Primary Care

For people with chronic conditions, the goal is not cure but maintenance to eliminate, minimize, or delay the effects of disability progression. Therefore, primary care involves a comprehensive assessment of medical, functional, nutritional, and psychosocial needs and arranges appropriate treatments and services to best meet the identified needs of the client and, if necessary, the caregiver. Primary care must be individualized, flexible, goal oriented, and holistic, focusing on the values and goals of the individual served. Additionally, ongoing care management must be accessible and financially responsible.

Relationship to Specialty Services

Primary care physicians are often defined as general practitioners, family practice and internal medicine physicians, and pediatricians. However, the primary physician in the care of a chronically ill individual may be a specialist such as an endocrinologist or a cardiologist. This is an important point, because recent studies have found that although “nearly 13 percent of the hours devoted to primary care in 1995 were provided by non-primary care physicians,” managed care seems to have precipitated a significant decrease in specialist involvement in primary care (Simon et al 1997). The needs of the client, not the constraints of a plan’s benefit package, should dictate the makeup of the primary care team.

Leadership of the Primary Care Team

Primary care teams function in a changing way according to client needs. Leadership may shift from time to time depending on these needs. For example, when medical needs are a priority, a physician, nurse practitioner, or physician assistant will likely assume the leadership role. When home safety or assistance with care delivery in the community is a critical or changing issue, a nurse or social worker may take the lead.

Primary Care Definition

The Institute of Medicine (1996) defines primary care as

“the provision of integrated, accessible healthcare services by clinicians who are accountable for addressing a large majority of personal healthcare needs, developing a sustained partnership with patients, and practicing in the context of family and community”

The process of care is linked to a clear communication system that includes everyone involved in the management of care, including the client, the family or caregiver, and all other support systems. The success of the team relies on a clear delineation of roles and processes for the team and its members.

Beyond the Medical Model

Within a CCN, the primary care team moves beyond the medical management model to respond to the ongoing process of managing care, including managing care across settings and providers and during any event related to or affected by a person’s chronic condition. The team is responsible for prevention, risk identification, care management and coordination, extended care pathway implementation, and client and family education. All efforts focus on minimizing and/or delaying disability.

Disability Prevention

The goal of disability prevention for people with chronic conditions is “to maximize an individual’s functioning, well being, and quality of life while achieving optimum care and cost outcomes” (Phillips 1996). Depending on the status of individual clients, prevention strategies can fall into three categories: primary prevention, secondary prevention, and tertiary prevention.

Disability Prevention		
Type of Prevention	Method of Prevention	Goal of Prevention
Primary	Education and lifestyle modification	Avoid disease
Secondary	Early detection and treatment	Minimize progression
Tertiary	Rehabilitation and interventions	Prevent functional decline

Primary prevention includes educational and lifestyle modifications directed at avoiding disease. The goal of secondary prevention is early detection and treatment of asymptomatic or early-stage diseases to minimize progression. Tertiary prevention focuses on rehabilitation services and early interventions to prevent functional decline.

Risk Identification

Risk identification allows providers to identify people who are at high risk of experiencing adverse health events (e.g., hospitalizations, nursing home admissions, functional decline, death) due to certain risk factors (e.g., age, living arrangement, chronic illness) (*Risk Identification: Exploring A Conceptual Framework and Identifying Implementation Issues* 1995). According to the Institute of Medicine, risk factors can be divided into three risk domains, biological, environmental, and lifestyle and behavioral (1991).

Risk identification serves the purpose of targeting areas for primary, secondary, and tertiary prevention, not merely for classification’s sake, but so that the appropriate interventions can be employed. The risk-identification process as defined by the NCCC includes health-risk appraisal, high-risk screening, and risk evaluation.

Care Coordination

Many models exist of how an individual’s care can be coordinated and managed over time, place, and profession. Within a network or system such coordination allows the client and family to have a single contact point. Aside from such altruistic reasons, however, systems rarely have any incentive to coordinate care unless they are at financial risk for the care provided. The Minnesota Senior Health Options (MSHO) program, a managed care demonstration for individuals eligible for both Medicare and Medicaid, uses a model in which enrollees have a designated healthcare coordinator. This care coordinator, usually a social work case manager or nursing case manager, is responsible for coordinating all needed services (e.g., medical care, transportation, social services, community-based services). The purpose of the MSHO model is to enhance enrollee access to appropriate services across the continuum.

Integrated care management includes several key elements, including providing person-centered care, emphasizing ongoing disability prevention, integrating a full and flexible array of services, targeting people at high risk, and managing care across the continuum (*The Elements of Integrated Care Management* 1995). In a primary care team model, one professional is usually responsible for working with the client and/or the caregiver and coordinating the

care at any given point in time. Within a primary care practice, for instance, a care coordinator may schedule followup appointments, answer basic questions, coordinate education that emphasizes self management, and facilitate access to other needed services. Because the needs of the chronically ill can be diverse and time consuming, such an arrangement can better support the work of the physician and other clinical staff.

Extended Care Pathways

For several years the NCCC has focused on the concept of extended care pathways (ECPs) as an important technique for integrating care management for people with chronic conditions over time and across settings. ECPs are a “standardized approach to multi-disciplinary care of an individual with a particular diagnosis” (*Conceptualizing, Implementing, and Evaluating Extended Care Pathways 1995*). In contrast to critical pathways, which are specific to care in a particular setting, ECPs apply to “the entire course of a condition and the full continuum of care.”

Keep in mind that the interventions used to treat people with chronic conditions are not necessarily well defined. Although healthcare has made strides in recent years in measuring effectiveness and tracking outcomes, the practice of medicine is still much more art than science. Evidence of inconsistencies in clinical practice and variations in utilization abound no less in the treatment of chronic illness than in the treatment of acute illness. More importantly, although individuals with chronic illness utilize a significant portion of healthcare resources, we know relatively little about the progression of chronic illness, the confounding relationship of comorbid conditions, or the effect of interventions (or combinations of interventions) over time.

Another issue is the tendency of the U.S. healthcare system to “over medicalize” the interventions needed for people with chronic conditions. Although many such uncertainties still exist, the system is becoming much more sophisticated in employing interventions at the right time for a positive impact.

Examples of Risk Factors in Each Risk Domain

Domain	<ul style="list-style-type: none"> • Genetic factors, such as one disease increasing the risk of another (e.g., diabetes increasing the risk for stroke) • Adverse effects of drugs (e.g., the sedating effects of psychotropic drugs increasing the risk of falling)
Environmental (social and physical)	<ul style="list-style-type: none"> • Lack of family support • Death of a spouse • Lack of transportation • Social stigma regarding dependence on wheelchair • Exposure to pollutants • Lack of access to adequate healthcare
Lifestyle and Behavioral	<ul style="list-style-type: none"> • Poor eating ability and inadequate diet • Tobacco use, alcohol use, drug use • Stress • Sedentary lifestyle • Inadequate coping behavior

Source: Risk domains as defined by the Institute of Medicine, 1991

Client and Family Education

The existence of a chronic condition may require more interactions with the healthcare system, more self-care management of the condition by the client, and more informal caregiving from family and friends. For all of these reasons, client and family education are essential within a CCN.

Clients and their families need to be taught how to manage the disease; this includes understanding such elements of chronic disease progression as improvement, maintenance, recognition of decline, and recognition of death. The focus of healthcare has predominately been on acute care illnesses; therefore chronic disease management and education are not things that most care systems do well. Healthcare professionals often feel unprepared to provide education and support, but such services are becoming increasingly important as a measure of quality care for the chronically ill. Patient educators, then, are an integral part of the primary care team.

The Evolution of Care Teams

The nature and culture of U.S. healthcare delivery is changing as systems become more integrated. The healthcare system has shifted from a delivery model consisting mostly of independent practitioners and institutions to a variety of multispecialty clinics, hospital systems, and alliances. As discussed earlier, primary care teams are composed of a variety of disciplines from across the continuum, including experts in nontraditional healthcare arenas such as home and community-based services, that tap the expertise needed to manage care effectively. Although a variety of care team models have been described in the literature, the cohesive and constructive nature of true “care teams” is seen only in pockets of delivery systems and in many cases only in the traditional institutional settings, such as hospitals. Innovative models of care teams in the outpatient and home and community-based settings are, however, making significant inroads into the healthcare system. Several examples of interdisciplinary care team models that can be utilized in the primary care setting for people with chronic conditions will be discussed later.

The concept of care teams is evolving as the individual segments of the healthcare field become increasingly aware of the interdependence of their work. Over the years, care teams have emphasized the multidisciplinary and more recently the interdisciplinary nature of working in teams. Some have evolved the concept even further into what are called interdisciplinary learning teams.

Multidisciplinary teams bring together different disciplines to meet the needs of the client, but care is still largely dictated by the physician, roles are set, and collaboration is not necessarily emphasized. Interdisciplinary teams are more collaborative in nature, patients and families are more integral to the process, and leadership of the team changes as needed. Interdisciplinary learning takes teams one step further and emphasizes a quality improvement process cycle and greater flexibility to meet the needs of clients and promote learning among the team members.

Evolution of Teams and Their Characteristics

Characteristics of Teams	Multidisciplinary Teams	Interdisciplinary Teams	Interdisciplinary Learning Teams
Focus	<ul style="list-style-type: none"> • Providing quality care • Achieving care outcomes 	<ul style="list-style-type: none"> • Providing quality care • Achieving care outcomes • May attend to process 	<ul style="list-style-type: none"> • Providing quality care, plus continuous improvement • Achieving care outcomes, plus team learning
Attitude Toward Change	<ul style="list-style-type: none"> • Accepts change 	<ul style="list-style-type: none"> • Accepts change 	<ul style="list-style-type: none"> • Stimulates and embraces change
Attitude Toward Diversity	<ul style="list-style-type: none"> • Recognizes diversity 	<ul style="list-style-type: none"> • Respects diversity 	<ul style="list-style-type: none"> • Capitalizes on diversity
Roles	<ul style="list-style-type: none"> • Fixed 	<ul style="list-style-type: none"> • Fixed but collaborative 	<ul style="list-style-type: none"> • Flexible and synergistic
Assumptions about Leadership	<ul style="list-style-type: none"> • Physician leadership assumed 	<ul style="list-style-type: none"> • Leadership is assigned or emerges according to the situation 	<ul style="list-style-type: none"> • Emerges according to the situation or need
Attitude Toward Patients and Families	<ul style="list-style-type: none"> • Consulted on plan of care 	<ul style="list-style-type: none"> • Variable range of involvement in plan 	<ul style="list-style-type: none"> • Partners in designing a plan
Timeframe	<ul style="list-style-type: none"> • Focus on intervention 	<ul style="list-style-type: none"> • Focus on intervention 	<ul style="list-style-type: none"> • Focus on intervention, plus future learning “feed forward”
Source of Knowledge	<ul style="list-style-type: none"> • Disciplinary expertise 	<ul style="list-style-type: none"> • Disciplinary expertise, plus collaboration 	<ul style="list-style-type: none"> • Expertise integrated • Team has collective awareness of its knowledge base
Attention to Process	<ul style="list-style-type: none"> • Incidental 	<ul style="list-style-type: none"> • Variable 	<ul style="list-style-type: none"> • Critical
Personal and Professional Growth	<ul style="list-style-type: none"> • Possible 	<ul style="list-style-type: none"> • May be encouraged 	<ul style="list-style-type: none"> • Expected and encouraged
Learning	<ul style="list-style-type: none"> • Evolutionary 	<ul style="list-style-type: none"> • Evolutionary 	<ul style="list-style-type: none"> • Central focus • Conscious cycles
Attention to Education of Next Generation	<ul style="list-style-type: none"> • No change in content • Increase in number of professionals 	<ul style="list-style-type: none"> • Shifts in content and educational process • Attention to teambuilding 	<ul style="list-style-type: none"> • Introduces new skills and educational processes • Includes nontraditional members

Source: Mason, Moore, Sciulli, Wadsworth, and Whitehouse. Great Lakes GITT. Developed November 1995, revised July 1996.

System Barriers to Implementation

The NCCC's vision of CCNs is a far cry from what currently exists in the healthcare system. Relationships within the healthcare community—between hospitals, nursing homes, home health, assisted living, and community-based services—and between professional disciplines is fragmented, inconsistent, and sometimes contradictory. But as systems recognize the impact of the chronically ill in terms of numbers, time, and resource utilization, barriers to change will become less difficult to overcome. As with any reform, the development of CCNs and primary care teams as the cornerstones of such systems will evolve as incentives emerge, consumers demand changes, and learning is adopted. In the end, however, changing behavior within a system may have more to do with finding the right financial incentives than with anything else.

Incentives

Without the right incentives, it is difficult to create integrated systems of care that focus on the needs of the individual. Reimbursement for care has historically been site dependent and medically focused. Providers and systems have been reimbursed based on the location of service delivery. There has been little incentive to create a care delivery system that more accurately reflects the actual needs of people with chronic conditions.

Despite its emphasis on primary and secondary prevention strategies, managed care organizations are often criticized for focusing too intently on cost savings in the short term and for not reimbursing a mix of services that would better promote the long-term management of chronic conditions. The danger of this approach for people with chronic chronic conditions is that saving money today may result in increased utilization down the road. This was demonstrated in the Diabetes Control and Complications Trial, which showed that long-term control of blood glucose levels resulted in a 76 percent reduction in retinopathy, a 60 percent reduction in neuropathy, and a 54 percent reduction in nephropathy (The Diabetes Control and

Complications Trial Research Group 1993). However, because such efforts may be very resource and cost intensive in the short run, and because the results may not become evident until years down the road (when the individual is under the care of another organization), there seems to be little incentive for managed care organizations to do anything differently (Bloomgarden 1994).

Managed care has the potential to provide the right incentives throughout the system to do the greatest good—to provide the most effective care at a reasonable cost. According to Stanley Jones, Director of the Health Insurance Reform Project, “chronic conditions involve health care needs that seem particularly suited to the kind of improved coordination and capitated payment associated with managed care” (Jones 1996). In fact, the structural characteristics of traditional HMOs—for example, a shared organizational identity and clinical culture, emphasis on preventive services, and centralized patient education—may be the key to providing good geriatric care (Wagner 1996). However, cost containment continues as the mantra in healthcare. Built-in financial disincentives may discourage healthcare organizations from becoming known for their ability to serve individuals with chronic conditions. Without risk-adjusted payments to compensate for high-risk, high-cost individuals, the threat of adverse selection creates “a constant tension in risk-bearing organizations between those who seek to develop and promote disease management programs and those who would like to develop the programs but keep them secret” (Harris 1996).

Current risk-adjustment methodologies under consideration by HCFA are based on hospital diagnoses and thus undermine efforts by providers to keep chronically ill and frail elders well and in the community. Adjustments to capitated payments should reflect the cost of serving those with chronic conditions in the most appropriate settings. Ideally, risk-adjusted payments should also

provide the right financial incentives for providers to develop the expertise and systems of care needed to meet the needs of the chronically ill.

Providers within CCNs who operate under integrated financing arrangements, with adequate payment adjustments to account for sicker and frailer clients, have the right incentive to manage and coordinate care across settings and to provide whatever combination of care is deemed most appropriate and cost effective for the needs of the client.

Information Systems Versus Information Process

People with chronic illness often access the healthcare system in many different places—physician’s office, emergency room, hospital, nursing home. However, the way information flows within and across systems in these settings is fragmented. In fact, tracking clinical data across settings and over time is virtually impossible. In reaction to this need to better understand resource utilization, healthcare organizations are now spending a great deal of money updating, linking, and/or implementing new information systems. For the most part, though, the implementation of new information systems will not be the magic bullet. Without careful consideration, information systems may only “speed up the mess” of unnecessary or inaccurate data. Organizations and providers need to determine which information is important and relevant enough to communicate, track, and analyze. What information do providers need to make informed decisions? What information is important to the client and/or the caregiver? What information is important to the healthcare system and its quality improvement efforts?

The primary care team needs to have access to better, more timely information. According to Robert Kane, the management of chronic disease can be improved through the use of an information infrastructure that helps “clinicians to think in more longitudinal terms, to recognize the continuous nature of chronic care, and to focus their attention on changes in patients’ status (Kane 1998). What the system needs then is not necessarily new technology but rather more integrated information

processes. This includes appropriate and open communication channels, defined uniform data elements, an effective data-collection system and longitudinal database, and an integrated information system. The data elements and information system should capture meaningful and relevant demographic, clinical, functional, and financial information. Important outcomes of such a system could include the development of registries that identify people with particular chronic illnesses in order to focus interventions; the facilitation of followup, including reminders; and the feedback of relevant information to the primary care team for quality improvement purposes (Wagner 1996).

Improving Systems and Care Outcomes

A Fragmented System Versus an Integrated System of Care

The U.S. healthcare system is organized to respond to the acute and urgent needs of individuals rather than to provide ongoing, long-term management and monitoring of chronic conditions. The system excels at taking care of people experiencing crisis situations but not at improving how people are cared for on a day-to-day basis.

The NCCC believes that CCN systems and processes promote provider collaboration across sites and toward common goals. The work of the primary care team as an integral part of the CCN should be in line with the goals of the organization. But as many healthcare organizations have discovered, gathering fragmented pieces into an integrated system is no small feat.

For that reason, the Self-Assessment for Systems Integration (SASI™) tool was developed as a way of conceptualizing, implementing, and measuring chronic care integration strategies within a network. Many of the organizational objectives included in the SASI tool directly support the work of primary care teams.

SASI™ Organizational Objectives

1. Governance structures that support goal development and improve the ability of individual care providers to work together as a single system
2. Management strategies and structures that support cross-site, interdisciplinary integration efforts
3. Information technology systems that allow providers in all settings to share meaningful information about clients, costs, and operations
4. Financing systems that promote systemwide management of cumulative costs, tied to care outcomes
5. Identification of the needs of high-risk populations
6. Provision of a full array of effective and efficient services
7. Care management that focuses on disability prevention and is organized around defined populations
8. Seamless care that is provided across settings and over time
9. Client involvement in care management and self-care activities

For more information about the SASI tool, call (612) 858-8999.

Value: Appropriate Utilization, Better Outcomes

In healthcare, value is often measured in terms of utilization and outcomes. The nature of a chronic condition requires that service utilization be tracked in increments of more than just one or two years. People with chronic conditions may go a long period of time without accessing the healthcare system and then “crash,” requiring significant resources. Measuring outcomes for people with chronic conditions is also difficult. In contrast to acute conditions where episodes are discrete and can be measured fairly readily, chronic illness has no endpoint except for death. Outcomes are measured in terms of disability progression, functional improvement, and maintenance. Some believe that quality should be measured differently across all categories of individuals: the well, the acutely ill, the chronically ill, the frail elderly, and those at the end of life. The goal of measures under these circumstances would be to examine whether providers and the healthcare system provide the right care at the right time.

For individuals with chronic conditions and for the primary care team, perhaps the most significant quality measures are patient satisfaction, quality of life, and disability prevention or delay. For the healthcare system—especially in situations where the system is at financial risk—utilization of services and the cost of care over time are also important measures. Robert Kane recommends the development and adoption of clinical glidepaths, where sets of parameters for each chronic condition are established as a way to measure expected course versus actual course of a condition (Kane 1998). Information relating to these parameters would be tracked, and deviations from the glidepath would trigger action by the primary care team. Clinical glidepaths and ECPs could be integrated so that progress would be continuously monitored and any needed care would be coordinated across time and setting.

Operationalizing the Concept: Getting from Here to There

The quest to build CCNs raises the question of how to transform current systems of care into integrated delivery systems.

Organizational commitment to the vision and values of such a system is imperative. Traditional organizational and structural barriers to integrated care must be broken down, and innovative strategies must take their place. The organizational culture will need to go through enormous change.

Once the commitment is there, how do we effectively organize the delivery systems, with primary care as the cornerstone, to care for people with chronic conditions? Innovative models of care exist. Much can be learned from these models and their experience in terms of the development of primary care teams; the coordination of care across sites; effective transitions between care, settings and providers; an orientation to prevention and wellness; a focus on patient-centered care and self care; an emphasis on integrated information systems to track care longitudinally; and integrated financing strategies. These models can serve to educate and replicate. Research is needed to better understand the cost, quality, and effectiveness of these various strategies.

Organizational Commitment

Operationalizing this primary care team concept is easier said than done. It requires a fundamental change in how medical and nonmedical services are perceived, coordinated, and used to meet the needs of the individual. The team concept also requires a change in work roles and organizational design, more collaborative work, different and expanded skill sets, new lines of responsibility, and a new level of accountability on the part of the team members.

Changing Behavior

Traditionally, healthcare professionals have not been trained to work in teams or to focus on the educational, psychosocial, and behavioral needs of their clients. Additional research findings and evidence regarding the effectiveness of a team approach to primary care would greatly aid in its adoption and acceptance.

Healthcare professionals readily respond to results that show promise in improving the management of care for chronically ill individuals. However, changing provider behavior and organizational culture is difficult. Implementing cultural changes and enhancing the use of teams requires structures, commitment, and leadership from the organization.

The use of the team concept has been more readily discussed in terms of inpatient care and nursing teams but is less demonstrated in primary care settings. This may be due to the nature of how services are financed. The introduction of Medicare's diagnosis-related prospective payment system for hospitals provided an incentive for more innovations along with the hope that it would decrease cost.

Criteria for Self-Management Education

- Content presentation focused on patient's perceived needs
- Practice and feedback in new skills, including decisionmaking and problem solving
- Attention to emotional and role management in addition to medical management
- Use of techniques to increase patients' confidence in their ability to manage their conditions
- Emphasis on patients' active role in physician/patient relationship

Source: Lorig 1996

Educating Individuals and Caregivers

Chronic illness requires an integrated, patient-centered focus for care. The client and his or her caregiver are an integral part of the primary care team and require support and education to empower them to effectively self-manage their care.

Individuals can learn to set their own goals, to solve problems, and to manage their behavior. Effective self management of chronic illness requires engagement in activities that promote health as well as monitoring their ongoing physical and emotional condition to allow appropriate decisions about care. Teaching individuals how to do this requires that a system commit resources to establishing programs that include trained staff, literature, and other resources such as videotapes, audiotapes, and interactive computer programs.

Collaborative management brings together clients, families, and providers to more effectively meet the challenges of managing a chronic condition (Von Korff et al 1997). Such a collaboration can only occur with trust and an ongoing relationship. Important elements include shared goals and mutual understanding of roles and responsibilities.

Kate Lorig developed a highly successful

low-cost alternative to traditional patient-education programs. The arthritis self-management program uses trained lay leaders instead of healthcare professionals to teach a self-management course (Lorig 1996). This program has been modified to meet the needs of individuals with other chronic diseases.

Models of Care

Although their focus is often on the elderly, several innovative programs can serve as model ways to use primary care teams more effectively. These include programs such as PACE and CHCC.

The Program of All Inclusive Care for the Elderly (PACE)

The Program of All Inclusive Care for the Elderly (PACE) is an innovative total-care program for the frail elderly modeled after On Lok in San Francisco. PACE, a Medicare/Medicaid-waiver project, puts all medical, restorative, social, and supportive care together in one organization, where most care is provided in an adult day health centers or the clients' home. PACE thus preserves the client's community residence, family relationships, and lifestyle. The PACE multidisciplinary team model is made up of physicians, nurses, social workers, therapists, drivers, health aids, and others as determined by the care plan.

PACE is a capitated model of long-term care that exceeds traditional Medicare and Medicaid benefits.

In 1995 there were 11 PACE programs in eight states. Congress recently passed legislation that would increase the number of PACE sites in future years. The PACE program has demonstrated important results such as the following.

Essential Elements of Collaborative Management

- Collaborative definition of problems, in which patient-defined problems are identified along with medical problems diagnosed by physicians
- Targeting, goal setting, and planning, in which patients and provider focus on a specific problem, set realistic objectives, and develop an action plan for attaining those objectives in the context of patient preferences and readiness
- Creation of a continuum of self-management training and support services, in which patients have access to services that teach skills needed to carry out medical regimens, guide health behavior changes, and provide emotional support
- Active and sustained followup, in which patients are contacted at specified intervals to monitor health status, identify potential complications, and check and reinforce progress in implementing the care plan

Source: Von Korff, Gruman, et al 1997

- Despite PACE enrollees' level of frailty, their hospital utilization rate per year is better than for the general Medicare population (2,476 days per 1,000 versus 2,512 days per 1,000).
- The average length of stay in the hospital for PACE enrollees is 5.4 days versus 8.1 days for the Medicare population (Harris 1997).

Cooperative Health Care Clinics (CHCC)

In 1991, Kaiser Permanente implemented a model called Cooperative Health Care Clinics (CHCC) where a multidisciplinary team facilitates an interactive process of care delivery in a group-visit format (Scott 1997). The team empowers the patient, who is supported by information and encouraged to make informed healthcare decisions. Most of the groups are comprised of seniors with multiple complex chronic health problems.

The goals of CHCC are to

- Evaluate the effectiveness of a new group-care model.
- Educate patients about their illness.
- Address patients' psychosocial needs.
- Increase patients' satisfaction with and participation in their care.
- Manage utilization more effectively by shifting care to the most appropriate provider type.
- Enhance patients' independence by maintaining their highest level of functional capacity.
- Reduce pharmacological problems including compliance, polypharmacy, and drug interactions.
- Conduct health maintenance more efficiently.

Monthly meetings on a regularly scheduled day last for one and one-half hours during which a topic/lecture is presented, interaction and interventions occur, and blood pressures are taken. Patients keep and update a patient care notebook that contains pertinent medical and emergency information, medical changes, and speaker handouts.

The CHCC provider team consists of the physician, nurse, health educators, dietitians, psychologists, and physical therapists. During the CHCC group meeting the physician answers patients' questions, makes recommendations for

treatments or tests, and renews prescriptions. After the meeting, health maintenance exams and individual visits are scheduled as necessary. The nurse facilitates health maintenance and provides triage and management of patient needs. Health educators, dietitians, psychologists and physical therapists may present topics or provide adjunct information at group meetings.

Preliminary analysis of the CHCCs found

- Improved perception of health status
- Decreased perception of depression
- Observed increase in function
- Increased satisfaction with physician
- Increased satisfaction with amount of time spent with patient
- Increased satisfaction with amount of health education

Other Care Innovations

In 1992, The John A. Hartford Foundation introduced the Generalist Physician Initiative to develop enhanced methods of providing primary care for the elderly that expanded the physician's scope of practice to include broader issues related to patients' psychological and social well-being. 10 sites are participating in this initiative. Descriptions of three are presented in this paper.

One other program, the Geriatric Care Coordination program at Sutter Health in Sacramento also has interesting preliminary results (Phillips-Harris, unpublished). The program used a risk-screening process to identify high-risk seniors enrolled in Medicare-risk plans. These individuals were assessed to identify their specific needs, and a care coordination process was created. The team of providers included a social worker, a geriatric nurse practitioner, and a geriatrician. The program showed statistically significant improvements in instrumental activities of daily living, activities of daily living, depression, and home safety. Due to the short length of the study and the small population size, however, no significant difference in cost was found.

Numerous Cooperative Health Care Clinic resources are available, including videos and orientation manuals.

For more information call (303) 344-7554 or fax (303) 344-7301.

Examples of Generalist Physician Initiatives and Findings

System Care Management

Model: System care management (SCM) is offered to older patients who need assistance in accessing appropriate health and social care services. SCM is designed to improve how primary care physicians do all that is necessary to integrate care for geriatric patients. Patient care coordinators (PCCs)—advanced-practice nurses with advanced training in geriatrics and adult care—are used in collaboration with primary care physicians to expand the continuum of services available to elderly patients.

Findings: Patients in the demonstration were 43 percent less likely than the control group to use the hospital and 44 percent less likely than the control group to use the emergency room. A cost-avoided analysis found that net savings of \$380,415 due to avoiding or delaying nursing home placement, hospitalization, and emergency room visits. Researchers also found significant improvements in patient satisfaction and physician satisfaction.

Source: *Implementation Manual for System Care Management* developed by United Health Services (UHS), Binghamton, New York.

Geriatric Collaborative Practice

Model: Multidisciplinary team management for rural elderly patients where primary care physicians are paired with nurse partners to manage panels of geriatric patients across the care continuum. This project enrolled more than 1,000 at-risk elders and tested the impact of the collaborative model in terms of patient outcome, provider satisfaction, health service utilization, and longitudinal patterns of care.

Findings: Consistently high patient, physician, and nurse satisfaction and decreased service utilization.

Source: *Geriatric Collaborative Care Model: Improving the System of Primary Care*, developed by The Carle Clinic, Champaign, Illinois. Available from Medical Group Management Association, (303) 397-7888, item #5048.

Complementary Geriatric Practice

Model: Physicians and nurse practitioners work together in the ambulatory clinic setting to provide primary care for frail elderly patients. The project's objectives were to create a sustainable model of care that had positive impacts on the provider-patient relationship, on patient health status, and on use of services. The complementary practice model was used with 442 geriatric patients at two clinics.

Findings: The effect of the model on the quality of the patient-provider relationship was strongly positive for patients age 80 and older. With regard to health and functional status one clinic showed that the complementary practice model had a significant impact on several measures, including instrumental activities of daily living limits, physical activity, and control over future health. The project did not see any effect on utilization.

Source: *Complementary Geriatric Generalist Practice Model: Final Report*, Henry Ford Health System, Detroit, Michigan

Conclusion: Looking Ahead

Primary care is an integral function of care assessment and delivery and involves the coordination of a broad range of care management services. Given the complexity of many chronic conditions, primary care plays a significant role in reducing and/or preventing the debilitating consequences of chronic illness. Within a CCN, the primary care team is proactive in relation to the natural evolution of the chronic condition and is accountable for the clinical and financial outcomes that define quality of care, including clinical, client satisfaction, and cost outcomes. The primary care team enables the client and caregivers to play an active role in understanding and managing the client's health.

As healthcare's highest-cost and fastest-growing group, the chronically ill are the biggest and most costly challenge to delivery systems and providers. Disparate funding streams and silos of care fragment today's healthcare delivery system. Individuals and their caregivers are frustrated and inadequately served by the lack of communication and coordination that occurs both within and between systems of care. Providers and practitioners work within systems with little integration

of care management functions, clinical and administrative information systems, or financing mechanisms that would facilitate the delivery of seamless healthcare across the continuum of services. In fact, physicians and other healthcare professionals are frequently not paid, trained, or empowered to coordinate the host of medical and nonmedical services that are needed. Health systems are frustrated by the lack of integration, but have little incentive to break down the silos of care that exist within their organization and among other service providers.

The bridge to the future requires a fundamental restructuring of our healthcare system, which requires a new set of skills and ideas. NCCC's vision of CCNs, with primary care teams as the cornerstone, promotes a framework for achieving these goals.

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The NCCC's mission is to serve as an operational laboratory for enabling innovative health networks to establish prototype systems for better serving persons with chronic conditions.

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