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Prevalence and Costs of Chronic Disease in a Health Care System Structured for Treatment of Acute Illness¹

Chronic illnesses account for 70% of deaths and for the expenditure of over 75% of direct health care costs in the United States, according to the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (1). Direct costs are now estimated at over \$1.5 trillion (2). Indirect costs of chronic diseases, in the form of lost productivity and nonreimbursed personal costs, add several more hundreds of billions of dollars each year. In a landmark study published in 1996, Hoffman et al (3) reported that in 1990 90 million people in the United States lived with a chronic disease or condition and 39 million people had more than one such condition. Extrapolating from these and other data, the Centers for Disease Control and Prevention estimated that as many as 25 million Americans have a chronic condition that is disabling (1). Although the literature does not support a single uniform definition for chronic disease, recurrent themes include the non-self-limited nature, the association with persistent and recurring health problems, and a duration mea-

sured in months and years, not days and weeks (3,4).

Since the prevalence of chronic diseases increases with age, increased longevity is a major contributor to the high and steadily rising prevalence of chronic diseases and the aggregate costs of care for people with them. At the turn of the 19th century, the life expectancy at birth for people in the United States was just over 47 years (5). One century later, life expectancy had increased to 77 years, an astonishing 30-year, or 64%, increase. The number of people in the country over 65 years of age increased from 3 million to 35 million (6).

Substantial contributions to increased longevity have come from advances in medicine, especially reduced infant mortality and the treatment and prevention of infectious diseases. Other important contributions have come from advances in public health measures, including improved sanitation and purification of water supplies. With people living longer, many diseases and conditions such as arthritis; cardiovascular ailments; and neurodegenerative diseases, including Alzheimer disease, have time to manifest.

Moreover, many diseases that were fatal in the past, such as type I diabetes, acquired immunodeficiency syndrome, and a number of cancers, have been converted to chronic conditions with prolonged courses and resulting in substantially improved life expectancy. This phenomenon has also contributed to the increase in the prevalence of chronic disease. Some of the diseases that have been converted from acutely fatal to manageable chronic conditions are very costly to treat over their full courses.

Prevalence of Chronic Disease

Input data for estimates of the prevalence of chronic disease come from a va-

riety of sources, including data from population surveys and reviews of insurance claims, which typically record the reasons for which patients have sought care and/or the diagnoses associated with the care episode. The ninth revision of the *International Classification of Diseases, Clinical Modification* (ICD-9-CM) (7) is probably the most widely used recording instrument in health status surveys. ICD-9-CM coding is also used widely in the processing of insurance claims. Since each disease or reason for care delivery has associated ICD-9-CM codes, the respective prevalence of diseases can be readily determined for any given data source that uses the ICD-9-CM system.

The National Health and Nutrition Examination Survey (8) and the Medical Expenditure Panel Survey (formerly, National Medical Expenditure Survey) (9) are two important surveys that provide nationally representative information about disease prevalence and costs for the entire population. Data on Medicare claims provide extensive information for persons over 65 years of age. Insurance data for younger populations are fragmented between carriers and are more difficult to access.

The sample sizes required for adequate statistical sampling and the complexity and cost of obtaining survey data preclude comprehensive annual surveys or studies of insurance claims data. As a consequence many, if not most, published estimates of disease prevalence are based on extrapolations from periodically available survey data to account for changes over time in factors such as population growth and changing age distribution.

Given the number of challenges in obtaining timely high-quality input data and the need to extrapolate to fill in time

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gaps, estimates of disease prevalence should probably be regarded as broadly indicative and directional rather than precise. Nonetheless, the magnitude of the population burden of chronic disease is eye opening and encompasses every organ system.

The American Heart Association, drawing on a number of data sources, estimated that a total of 64.4 million Americans have one or more types of cardiovascular disease (10). Hypertension alone, defined as a systolic pressure above 140 mm Hg and/or diastolic pressure greater than 90 mm Hg, accounts for afflictions in 50 million people (10). Coronary heart disease affects 13.2 million people, manifesting as acute myocardial infarction in 7.8 million and as chest pain syndromes in 6.8 million (some people experience both, which accounts for the higher sum of the components vs the overall prevalence) (10). Five million people live with congestive heart failure, and 4.8 million have strokes each year (10). Cardiovascular diseases, including stroke, accounted for around 40% of all deaths in the United States in 2001 and were considered a contributing factor in another 20% (11).

Another category of chronic disease with a very high prevalence is arthritis, which is estimated to afflict 50–70 million Americans (12,13). The lower end of the range includes people with physician-diagnosed arthritis, and the higher end comes from population surveys in which people were asked to report symptoms of joint disease. Disability due to arthritis and back pain is substantial (1). Arthritis and back pain account for over one-third of all non-mental illness-related disability among persons over the age of 15 years in the United States (1). A report issued by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (12) noted that the number of Americans with some form of documented arthritis will increase by 50% by the year 2020, owing to the aging of the population, and that there will be an increasing burden not just to individuals but to the economy.

Other numerically important chronic diseases are asthma (14), with an estimated 15 million individuals affected, and diabetes (15,16), with an estimated 17–18 million people affected, including almost 6 million who have not been formally diagnosed. Both of these diseases are associated with substantial disability.

Chronic neurodegenerative diseases are also widely prevalent. These conditions are often challenging to diagnose correctly and are among the most diffi-

cult to manage because of their effect on both patients and families. An estimated 4 million Americans have Alzheimer disease (17), a condition that robs people of their ability to remember and reason and therewith steals their human identity. Parkinson disease (18) affects 1.5 million people in the United States.

Blindness and hearing loss are chronic conditions that both will increase with the aging of the population. A longitudinal study by Lee et al (19) in 20 325 representative Medicare beneficiaries demonstrated an increasing prevalence of three major eye diseases—macular degeneration, glaucoma, and diabetic retinopathy—over a 9-year period of study. Half of the surviving cohort had at least one of the diseases.

Mental disorders are also often difficult to diagnose or even to classify as chronic or acute. The Surgeon General of the United States estimated (20) that 19% of the population manifests evidence of a mental disorder within a given year, 3% have addictive and mental disorders, and 6% have addictive disorders alone, for a total of approximately 30% of the total population. Severe depression is a major cause of disability and lost days from work.

Direct and Indirect Costs Associated with Chronic Disease

In the study by Hoffman et al (3), the costs of caring for patients with chronic diseases were projected for the year 1990. The estimated total cost for care of patients with chronic diseases was \$659 billion, divided between direct costs of \$425 billion and indirect costs of \$234 billion, a ratio of just under 2:1.

Direct costs of care were determined (3) by reviewing insurance payments and other payments to individual providers and provider organizations for care episodes and payments for the purchase of prescribed medicines and other medical equipment or supplies. All costs of care for a person with chronic disease were considered chronic care costs, whatever the actual reason for the care. The encompassing nature of this definition has not been explicitly noted in subsequent references to this work, although, by any measure, the costs for the care of chronic disease would still be staggering, even with a more restrictive definition.

Indirect costs, although real, are more difficult to determine and are highly dependent on definition and even philosophy. Hoffman et al (3) defined them broadly in terms of morbidity and mor-

tality costs. Morbidity costs were defined as lost economic output from days of missed work and imputed costs for home care by family members or others not in the labor force. Mortality costs also encompassed projected economic losses, assuming that an individual would have remained gainfully employed over his or her otherwise estimated life expectancy, for work absent the cause of death.

Chronic Disease and the Structure of the U.S. Health Care System

There are a number of features of the current health care system in the United States that impede efficient high-quality care of patients with chronic disease or who are at risk for developing a chronic disease. Most important, despite the high prevalence of chronic diseases, the health care system in the United States is still fundamentally designed to deliver ad hoc episodic care to patients with acute illness or acute manifestations of chronic illness. Acute care hospitals dominate the organizational structure of the health care system and account for over 30% of health care expenditures (2).

The heavy inpatient focus of hospitals is not cost-effective for the management of chronic disease; from a hospital perspective, chronic disease is too often managed as a series of admissions for acute exacerbations. Data for diseases such as asthma and congestive heart failure (4,14,21–23) clearly indicate that cost savings and quality improvements come from what happens over the long term outside of hospitals to prevent acute episodes from occurring. The health care system, as currently structured, is at its best when an acutely ill patient presents for care of an acute illness or condition or when a patient with a diagnosed condition requires an elective procedure or other therapy.

Hospitals too often treat their outpatient activities as secondary adjuncts to their core inpatient missions or as “loss leaders” for high-revenue admissions and have not come close to redesigning their activities for the contemporary needs of patients with chronic disease through adoption of disease-management programs and comprehensive information systems. Outpatient facilities built on hospital campuses can be burdened with the high cost structure and overhead of associated inpatient facilities, which discourages robust investment in lower-margin outpatient care. Hospitals are only now investing in electronic medical records systems that encompass outpa-

tient, as well as inpatient, care for patients. Such systems are necessary for the efficient organization and tracking of long-term care of chronic disease.

Many physicians' practices are also still organized, in large part, in relationship to hospitals on the basis of employment or staff privileges, especially in academic and metropolitan settings. Practice patterns for these physicians will be highly influenced by hospital dominance of the delivery system for the foreseeable future. Forty percent of physicians in community practice settings are in solo practice. They are fragmented organizationally and have no structural basis through which to deliver coordinated care: no common medical records system or way to track disease progress together. Hospitals and large physician groups are the only nongovernmental provider organizations, in the aggregate, with access to the substantial amounts of capital resources required for creating new care paradigms to manage chronic disease, including investment in information technology.

A second major set of issues deals with payment systems for health care. The dominant payment mechanism, even many decades after the concepts of managed health care and capitation were introduced, continues to be fee-for-service payment. The units of service are typically defined by the Current Procedural Terminology (CPT) (24) system maintained by the American Medical Association.

The structure of fee-for-service payments for CPT-coded procedures does not come close to adequately rewarding efforts by physicians, hospitals, or other health care organizations for prevention programs, including counseling and patient education. The CPT-based fee-for-service system does not allow payment for many of the specific services known to improve quality and reduce overall costs, such as home monitoring of patients with congestive heart failure. Insurance companies will pay for treatment of pulmonary edema in a hospital but not for a phone call to see how a patient is doing at home. Gruman and Gibson (23) noted, "Insurance, for example, will pay for the amputation of a limb for diabetes related gangrene but not for the sustained diabetes self-management and monitoring that can lessen the probability of needing more costly interventions later." The majority of reimbursable CPT codes are for services rendered in the treatment of acute illness or of acute ex-

acerbations and complications of chronic conditions.

In the current fee-for-service reimbursement system, providers who manage chronic diseases effectively risk losing out twice: first, because the payment system typically does not compensate them for the extra costs associated with more effective management and, second, because the savings (due to more effective management) from reduced hospitalizations and reduced treatment of long-term complications remain with the insurance company and are not passed on to the provider who did the extra work to provide better care. These are powerful financial disincentives to providers and hospitals that earn their revenue service by service and admission by admission. Likewise, fee-for-service discourages the kind of teamwork between physicians that is desirable in caring for many patients with complex problems. Pay-for-performance systems are beginning to address the need for payers to share savings from more effective care with providers and to reward providers for achieving better results.

The ability to use insurance-premium dollars wisely to maintain health through preventive services and the ability to reduce long-term health care costs by reducing the likelihood of future illness would appear to be a reasonable strategy for insurance companies and is one of the fundamental assumptions underlying the concept of health maintenance organizations (HMOs). In capitation arrangements with HMOs, providers receive contracted payments and accept risk for the costs of delivering needed care. In theory, more money spent up front on prevention should be cost-effective and reduce downstream costs. However, in the report of the National Committee for Quality Assurance, *The State of Health Care Quality: 2004* (22), major gaps between best practices and health plan performance continued to be observed, including gaps in indicators for chronic disease. For control of high blood pressure, the average performance among the health care plans surveyed was only 62%. At the 90th percentile, control was achieved in 71% of patients. The National Committee for Quality Assurance asserts (22) that if all Americans with hypertension received care at even the 90th percentile of performance, 15 000–26 000 deaths annually could be prevented and sick days could be reduced by more than 21 million.

Why, then, has there not been more interest by insurance companies in pro-

viding and even insisting on more preventive services for patients with chronic disease and implementation of comprehensive disease-management programs by providers, and why have HMOs not scored better on the National Committee for Quality Assurance surveys? While the complete answer is complex, one obvious point is that the high turnover of clients from year to year is a disincentive for insurance companies, as well as for HMOs, to invest in preventive care. Simply put, if a client changes insurance coverage, some organization downstream is more likely to benefit from the salutary effects of the investment in prevention, so why spend the money? The Kaiser Family Foundation survey (25) of employer health benefits for 2004 reported that 56% of firms that offer health care benefits shopped for a new plan and that 31% of those changed insurance carriers. This is hardly a prescription for long-term investment by an insurance company, but it raises the interesting question of why employers are not pushing harder from their side to realize long-term benefits of better preventive care. New employer-initiated pay-for-performance plans such as Bridges to Excellence are beginning to address this point.

Radiology and Chronic Disease

Imaging services are obviously of direct importance in the diagnosis and long-term management of many chronic diseases and conditions. Cancer care is heavily structured to involve imaging, and multi-detector row computed tomography (CT) is opening new doors in many areas, including the heart and vascular system. Imaging is literally the guiding hand for diagnosis of musculoskeletal disease.

At the same time, relatively little investment has been made in the study of the optimum use of imaging or how to integrate imaging into evidence-based disease-management programs of the kind highlighted by the Institute of Medicine in its landmark publication, *Crossing the Quality Chasm: A New Health System for the 21st Century* (4). Radiologists will need to address these issues in a much more robust way than in the past because of increasing pressures to reduce overutilization of all medical services, especially rapidly growing ones such as imaging. How often should imaging be applied? which method should be used? and how much radiation is acceptable? are all questions germane to the care of people with chronic disease who are

likely to need imaging services over a period of time.

The establishment of the American College of Radiology Imaging Network (ACRIN) (26) under the direction of Bruce Hillman, MD, is an important step in the direction of strengthening technology-assessment research in imaging. ACRIN has initiated clinical trials aimed at establishing the efficacy and, therefore, the role of emerging imaging methods. Current trials address questions of major interest, such as the role of digital mammography versus screen-film mammography and that of CT colonography versus conventional colonoscopy. A major trial is underway to assess the costs and benefits of radiography versus those of lung CT imaging for lung cancer. Broad participation by radiologists benefits ACRIN by increasing patient recruitment into trials and is highly encouraged.

Restructuring the Health System for Care of Chronic Disease

The issue of chronic disease is not going to go away; quite the opposite, the number of affected people will increase, as will costs. Chronic diseases are especially hard on the elderly because they result in disability and diminished quality of life (6). Much of the knowledge is in hand to achieve better outcomes and reduce costs in the care of people with chronic diseases: Better prevention, more patient education, involvement in self-help and empowerment, systematic use of evidence-based disease-management programs, closer adherence to best practices, information systems with patient-focused electronic records to track disease progress and therapy, and a team approach by physicians and other care givers are all proven winners (14,16,21–23). The health care system in the United States, now dominated by inpatient facilities, needs to recast its basic mission as that of keeping people out of hospitals through life-long health care programs and the prevention of complications of chronic diseases.

Paying for the care required in unnecessary episodes of acute illness because of gaps in preventive care will reward failure and increase overall health care costs and may create disincentives for individual providers to optimize long-term care of people with chronic conditions. Adherence to proven best practices must be a commitment made by every physician and provider organization. The payment

system must be rebuilt to reward providers for keeping people as healthy as possible and out of hospitals as much as possible, whether these are accomplished through pay-for-performance plans or other approaches. Until the financial incentives are aligned to compensate providers for doing that, it will not happen enough. The reimbursement system must recognize and reward the extra work and infrastructure investments necessary to achieve improved quality in the care of patients with chronic disease. All stakeholders in the health care system—including patients, providers, payers, the public, and the government—should now recognize the growing imperative of caring for people with chronic diseases and should come together to design better structures for lifelong continuity of care, with emphasis on evidence-based practice and disease prevention.

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