

Who Cares: Chronic Illness in America

The terrorist attacks of September 11 changed the face of America. They not only killed thousands of people in New York, Washington, and Pennsylvania, but the acts of terror also changed the way most of us think and act. And while this cataclysmic event may have reawakened the American spirit, it also dampened our ability to address a host of other problems, including those in healthcare.

Today, the number one issue for virtually every healthcare institution is not chronic illness but disaster preparedness. Hospitals, physicians, nursing homes, and home care providers are heavily immersed in trying to cope with the possible threat of anthrax, smallpox, or other biological attacks. While it is critical that we prepare for the potential of a medical disaster, we cannot ignore the insidious and destructive forces of other diseases and disabilities that are poorly served by our crisis-oriented, acute care approach and that continue to plague millions of Americans each and every day.

Today, people with chronic conditions, such as heart disease, lung disease, asthma, arthritis, and Alzheimer's disease account for more than 77 percent of all healthcare expenditures. Nearly one in four workers between the ages of 25 and 55 is absent from work one day a week due to a chronic condition. Over 9 million people with chronic conditions are uninsured. Sixty-five percent of Medicare beneficiaries 65 and older have two or more chronic conditions and account for 95 percent of all Medicare expenditures. Last year, over 510 billion dollars were spent on medical care for people with chronic conditions.

Recently, Lou Harris conducted a national survey for Partnership for Solutions, a national project on chronic care sponsored by The Robert Wood Johnson Foundation. Survey results showed that people with chronic conditions have great difficulty obtaining the healthcare they need and want. Eighteen percent of those with chronic conditions reported that they received contradictory medical information in the last year. Fifty-six percent said they did not receive adequate medical care. Seventy-nine percent reported that it is somewhat or very difficult to obtain adequate insurance. Ninety-five percent of all physicians said coordination of care is a serious problem.

There are many programs available for people with chronic conditions. On the surface, one can say, "This is good news!" Yet most people in need do not fully understand what is available to them, and most public and private programs for chronic illness care use different and many times conflicting approaches.

Many people think that Medicare covers long-term care, but it does not. Many people think that Medicare is for the elderly and Medicaid is for the poor. They assume that there is little or no overlap between these programs. Yet, 28 percent of Medicare expenditures and 35 percent of Medicaid expenditures are related to those dually eligible for Medicare and Medicaid. Many people think that long-term care insurance can fill the gap for our nation's elderly, but most older people cannot afford the premiums involved. Many people point to the rich benefits offered by employers, but in 1999 an estimated 42 million Americans were uninsured, which is



17.5 percent of those under age 65. Some companies are dropping coverage for some workers or passing on responsibilities for workers to cover rate increases that exceed the rate of their salary increases.

The fact is—our healthcare system is out of date and out of touch with the majority of people it serves. For example, children with asthma routinely end up going to the emergency room with breathing difficulties because no other options are available. Too often a physician's preferred treatment is drug therapy when simply educating parents about environmental factors, like eliminating dust mites and purifying the air, could avert the next medical crisis. People with diabetes can reduce disease and the onset of disability through diet, exercise, and blood sugar monitoring, yet our healthcare system consistently treats diabetic symptoms with medication and routine office visits. People with hip fractures and strokes routinely go through repetitious and cumbersome admission and discharge procedures and receive therapy from a potpourri of unrelated specialists. Many people with heart disease receive care from multiple physicians and wonder why their doctors never talk to one another. Millions of people need long-term care, yet these people and their families invariably find our care system to be a burdensome obstacle to getting that care.

A reactive, crisis-oriented, biomedical model of care drives current healthcare methods. This model significantly undervalues the importance of nutrition, mental health, help with activities of daily living, the role of families, and the impact of environmental circumstances. It frequently ignores the importance of prevention. For example, a loose rug is a hip fracture waiting to happen, and dust mites send people with asthma to the emergency room. The current model minimizes the interdependent nature of chronic illness. For example, a diabetic person's depression can affect their appetite, which can result in malnutrition, which will negatively affect their diabetes, which might result in hospitalization and/or death. Seldom is the ongoing nature of chronic illness taken into account. For example, we know that there is a direct relationship between heart disease and a prior history of smoking and stress, and we know that a high percentage of people with diabetes have hypertension and that diabetes can lead to end-stage renal disease. Yet we frequently treat each of these conditions as unrelated events.

Most healthcare professionals are decent, caring people. We can proudly say that our American healthcare institutions are the best in the world. We can look to our hospitals, physicians, and other healthcare professions with pride, knowing that no other place on earth is blessed with as much medical talent or more advanced medical technology. The problems we face are not related to people with harmful motives. The problems of chronic illness care rest in how we train our healthcare professionals, in how we finance healthcare services, and in how we organize our benefits and services. It rests in the infrastructure of healthcare operations.

To illustrate my point, let me share with you testimony from Dr. Alan Lazaroff, director of geriatric medicine at Centura Health in Colorado, who specializes in chronic illness care. Dr. Lazaroff reports—

"Much of my most important work is unrecognized and uncompensated—adjustment of medication, early detection of problems, referrals to and coordination of other services,



teaching and counseling. If I hospitalize a patient, I can bill Medicare every day I make a hospital visit, never mind whether this is the most appropriate treatment. If I meet with family members of a patient with Alzheimer's disease, coordinate with other professionals, counsel patients and families about both the benefits and limitations of aggressive treatment, and help my patients cope with the emotional consequences of their illness, I can bill nothing. I may be able to improve quality of life at the same time that I reduce inappropriate and unproductive hospitalizations, ICU care, and emergency room visits, but the more I focus on preventing or delaying the progression of disability, and the more money I save Medicare, the less I am paid. Something is terribly wrong with a system that rewards the unnecessary use of high-cost, high-tech services for a patient population that is equally dependent upon a vast array of supportive services and which penalizes practitioners who provide the services needed most, often at a lower cost."

It is easy to point fingers, but finger pointing won't bring about change. Success requires all parties to rise above self-interest and work together to find real-world solutions to one of the most complex healthcare problems of our time.

On Monday evening, October 29 at 10:00 p.m., WETA, Channel 26 in the Washington D.C. area will air a program entitled "Who Cares: Chronic Illness in America." The program, produced by Fred Friendly Seminars, explores the challenging circumstances that are played out by individuals, families, and healthcare professionals as they struggle to cope with a broad spectrum of chronic conditions. The program is moderated by award-winning journalist John Hockenberry. The panelists include doctors, caregivers, journalists, students, and family members who know the dilemmas and the tough choices of chronic illness first hand. The purpose is not to find blame but to help bring clarity to this dilemma and to serve as a catalyst for change in resolving this most difficult of healthcare problems.

These are difficult times, for sure. Our nation is threatened by acts of terror. Our nation cannot shrink from its national and international responsibilities. Yet, as we respond to this larger crisis, it is important to pay attention to other crises that rest at the core of our healthcare institutions.

Chronic illness is the most pervasive, insidious, destructive, and life threatening healthcare problem in America. The way we finance, administer, and deliver healthcare is fundamentally out of sync with the nature of chronic illness. The time to resolve this internal crisis is not tomorrow—but now.

