



THE PRESCRIPTION FOR LONG-TERM CARE

Long-term care is generally portrayed as a disembodied health care entity, isolated from the continuum of care that it rightly belongs to. People with chronic medical conditions—such as diabetes, arthritis, Alzheimer's disease, and heart disease—are served by this continuum of care and require long-term treatment when functional status and independence are compromised. Providing high-quality health care for chronic conditions that will delay the need for long-term care services should be one of our highest health policy priorities. Yet the inadequacies of health care for chronic conditions are rarely discussed in forums on the emerging crisis of long-term care.

Approaching long-term care as an isolated problem has fostered a focus on providing and paying for long-term care rather than preventing it. So the obvious needs to be stated: Improving the care of chronic illness will have the single greatest impact in reducing the need for long-term care services and averting the growing problem of long-term care.

The need for long-term care is often envisioned as an inevitable event—as if the day a patient will need long-term care is etched in stone at diagnosis of a potentially disabling chronic illness. But long-term care services are actually a range of options that may be required to a greater or lesser degree depending on many factors, including access to high-quality health care and

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prevention of common complications of illness. The need for long-term care services is also determined by the self-management skills of the patient, the preparation and support of the caregiver, and the suitability of the home environment.

We already have the knowledge to improve care for chronic illness and reduce the need for long-term care. We understand the natural history of chronic conditions as well as the common complications. Every physician treating the chronically ill can recite the common scenarios that result in complications and often herald a downward spiral: the hypertensive patient who has a stroke because he hasn't taken his medication, or the patient with Parkinson's who falls and breaks her hip because she is taking numerous sedating medications. Although chronic conditions are diverse, all have the potential for more precipitous decline when emphasis is not placed on prevention. And a surprising number of common themes exist—even among the most diverse chronic conditions—including the need for education, the prevalence of depression, and the risk of caregiver burnout.

People with chronic conditions need different services than those with short-term and self-limited illnesses. They need education, counseling, and training to learn the skills of self-management, including communicating with the physician, monitoring symptoms, providing feedback after new interventions, managing complex medications, and coordinating interdisciplinary care. People who never learn these skills (or who lose them) are at high risk for a broad range of costly medical complications.

It sounds simple enough. Why don't physicians recommend and prescribe the preventive services that meet the needs of the chronically ill? Why not offer self-management courses to teach



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the skills necessary for living with chronic conditions? Why not recommend care managers when the patient is unable to responsibly carry out the care plan? Why not obtain a home evaluation to recommend and implement modifications to maximize safety and delay dependency? Because both traditional medical practice and health policy have fostered a system of short-term care, not long-term care. The infrastructure exists to repair the fractured hip or treat the depression, not to prevent these problems from developing.

Neither the patient nor the physician recognizes the degree to which the "doctor's orders" are governed by public policy and insurance regulations (which are one and the same for those covered by Medicare). The illusion that the physician has the power and autonomy to deliver high-quality care for chronic conditions prevails.

A CASE SCENARIO

Mr. and Mrs. Nelson are at the end of their rope. Mrs. Nelson has brought her husband to see a new physician, telling him that he is their "last resort." Mr. Nelson's Parkinson's disease has steadily worsened over the last year; he is having problems walking and maintaining his balance and has fallen several times. He is increasingly confused and agitated, especially at night. Urinary frequency has progressed to incontinence, and Mrs. Nelson can barely support her husband's weight to help him to the bathroom.

Mrs. Nelson breaks down into tears in the office as she describes how she is worn out and has her own medical problems. Mr. Nelson sees many different specialists for Parkinson's disease, hypertension, heart disease, and prostate cancer. However, he and his wife arrive for this new consultation with no medical records and are unable to list his current or previous medications, although "many new ones have been added recently." The Nelsons have also lost their means of transportation because Mr. Nelson can no longer drive.

With limited history available, Dr. Johnson is in the dark about Mr. Nelson's medical history, the previous diagnostic workup, or recent changes in medications. He doesn't know what has already been tried, what has been successful in the past, and what has failed or resulted in side effects. Dr. Johnson suspects that the patient is oversedated as a result of complex drug interactions and adverse effects—a problem requiring full access to the medical history and collaboration among half a dozen treating physicians. He is also concerned that neither the patient nor the caregiver can carry out the required complicated medication adjustments.

The physician confronts this complex list of medical and social problems with a sense of hope-

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lessness—not because the medical problems are insurmountable, but because they require a health care infrastructure that doesn't exist. Both physician and patient share the frustration and helplessness that come from struggling with a chronic disease process that the health care system was never designed to treat.

OVERLOOKING THE NEEDS OF THE CHRONICALLY ILL: NEGLECT OR DENIAL?

In an age of unprecedented communications technology, why does no mechanism exist for a physician to obtain even basic medical records for the patient who arrives without them? Increased life expectancy has brought people into their seventh, eighth, and ninth decades—but with multiple concomitant medical conditions, long medication lists, and numerous attending physicians, nurses, and therapists. When the complexity of care overwhelms the patient and caregiver, supervision by a care manager can ensure that a care plan is carried out and that supportive services are targeted to identified needs. Although the concept of interdisciplinary care by a "team" is acknowledged as a goal, public policy has not promoted the technology or reimbursement that is fundamental to the collaborative efforts of health care providers.

Basic health care for chronic conditions involves hours of physician and staff time searching for medical records, obtaining the results of diagnostic tests, communicating with multiple care providers, completing myriad forms, and returning the calls of patients and family members. These services and the increasingly stringent requirements of medical documentation go completely unreimbursed. Physician and staff time to carry out Mr. Nelson's care plan will easily exceed the time of his initial office visit.

A bias toward short-term care rather than chronic illness care is perpetuated by public policy as well as factors that are deeply embedded in our culture and the traditions of medical practice. As a society, our emphasis is largely on identifying a cure for chronic illnesses rather than improving the care of chronic conditions. Advocacy groups for chronic illnesses place their major efforts on fund-raising and lobbying for research to find cures, with little energy directed to improving the quality of care or quality of life of those afflicted. Medical research is a source of great hope and progress, but no realistic prospect exists that chronic illnesses will be abolished. Nonetheless, an unmistakable collective denial is at work in the unrelenting push to abolish infirmity while issues of care and function of the disabled are neglected.

Fund-raisers understand well that "cure sells better than care." The media are eager to feature



the latest medical breakthrough in their headlines, but stories about improving continuity or coordination of care are rarely covered. The overselling of medical advances has raised public expectation to a level that can rarely be satisfied; the new pill for arthritis reduces, but does not eliminate, pain and the new surgical intervention for Parkinson's disease can reduce some, but not all, troubling symptoms. How do you summon a patient's fullest effort to adjust to his illness when the focus is on curing the illness?

The expectation of full relief from symptoms often results in dissatisfaction and despair, but accepting chronic illness as an ongoing process of adjustment and compensatory responses often results in a sense of control. The traditional role of the patient as a passive recipient of health care is at odds with the essential requirements for living successfully with a chronic condition. High-quality health care requires a new skill set for self-management; medical care suffers when the patient and caregiver are not fully engaged in this process. The benefits for both the active patient and the caregiver are improvements in continuity of care and medical compliance as well as restora-

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tion of control, self-esteem, and dignity to the family and patient.

HELP WANTED: NEW MODELS OF CLINICAL PRACTICE FOR CARE OF CHRONIC CONDITIONS

Medical progress in the 20th century transformed the challenge of conquering acute illness to one of confronting the long-term needs of chronic illness. Along the way, treatments for virtually all chronic medical conditions were developed, prolonging life expectancy for many common disorders. But medical training and practice have also not made the transition from the traditional focus on acute problems to an interactive process of ongoing care of chronic conditions.

Even as the pendulum swings from medical specialization to primary care, the approach to patient care remains largely problem oriented, an approach that is a relic of the acute care era, when a "presenting complaint" was an appropriate starting point for differential diagnosis and management. In contrast, high-quality care of chronic conditions requires a much broader focus that encompasses issues of prevention, functional status, behavioral adjustment, family issues, and long-term planning. Anticipating problems, the heart of preventive medicine, is an awkward appendage to the problem-oriented approach. Partly for this reason, preventive medicine continues to be applied piecemeal rather than assuming its rightful position as the major driving force of general medical practice.

Physicians become ever more proficient at the pharmacological and surgical approaches to disease, but the basic skills of responding to the day-to-day needs of individuals learning to live with chronic symptoms have not been embraced as the purview of medical practice. Physicians have little, if any, training in the functional correlates of cognitive and motor dysfunction. For example, what level of muscle weakness or incoordination is associated with the inability to care for oneself? What level of cognitive function is necessary for driving, basic shopping, or money management? Disability insurance forms routinely ask these questions of physicians who are not prepared to make these judgements.

Medical training rarely includes information about assistive devices for the disabled, including canes, walkers, wheelchairs, or safety bars for the home. Innovative models of continuity or interdisciplinary care are the exception, even though these qualities are central to quality care for chronic illness. Clinical research trials rarely focus on nonpharmacological issues, such as exercise, education, counseling, communication, and safety. The growth of outcomes research—studying the impact of clinical interventions on functional

SUGGESTED READING

Thomas Bodenheimer, "The American Health Care System: The Movement for Improved Quality in Health Care," *New England Journal of Medicine*, vol. 340, 1999, pp. 488-492.

Daniel Callahan, *False Hopes: Overcoming the Obstacles to a Sustainable, Affordable Medicine*, New Jersey, Rutgers University Press, 1999.

James S. Goodwin, "Geriatrics and the Limits of Modern Medicine," *New England Journal of Medicine*, vol. 340, 1999, pp. 1283-1285.

Institute of Medicine Committee on Quality of Health Care in America, *Crossing the Quality Chasm: A New Health System for the 21st Century*, Washington, D.C., National Academy Press, 2001.

Carol Levine, "The Loneliness of the Long-Term Care Giver," *New England Journal of Medicine*, vol. 340, 1999, pp. 1587-1590.

Kate Lorig, Halsted Holman, David Sobel, Diana Laurent, Virginia Gonzalez, and Marian Minor, *Living a Healthy Life with Chronic Conditions: Self-Management of Heart Disease, Arthritis, Diabetes, Asthma, Bronchitis, Emphysema and Others*, Palo Alto, CA, Bull Publishing Company, 2000.

Farrin A. Manian, "Whither Continuity of Care?," *New England Journal of Medicine*, vol. 340, 1999, pp. 1362-1363.



status and quality of life—is a valuable opportunity to gain insight into the relative cost/benefit ratios of nonpharmacologic and pharmacologic approaches.

MR. NELSON'S EPILOGUE

Dr. Johnson initially recommended hospitalization at either the local hospital or rehabilitation facility, but this request for authorization was denied by Mr. Nelson's insurance company. So, after obtaining recent medical records, he told the Nelsons how they could gradually taper and discontinue certain medications while introducing others with fewer side effects. He ordered new laboratory tests as well as a magnetic resonance image scan of the brain to ensure that no other injuries resulted from Mr. Nelson's frequent falls. He also recommended consultation with a neuropsychologist to formally evaluate his cognitive function, a rehabilitation therapist to optimize his balance and safety, and a urologist to reevaluate his urinary problems. The Nelsons left with a handful of new prescriptions, medication schedules, instructions, and an appointment to return to Dr. Johnson in three weeks.

Three weeks later, Mr. Nelson did not return for his appointment. What happened? Mrs. Nelson was unable to follow Dr. Johnson's recommendations because they were too complicated. Besides, she could not arrange transportation to the lab, the MRI center, the rehab center, and the pharmacy. But one week after seeing Dr. Johnson, they kept a previous appointment with another physician, Dr. Reynolds. He knew nothing about Dr. Johnson's advice, and when Mrs. Nelson stressed that her husband was awake all night long, he prescribed a new sleeping pill and gave them a sample pack to get them started. Sedated and unsteady on his feet, Mr. Nelson fell and fractured his hip, which required surgery. He underwent rehabilitation but ultimately was transferred to a nursing home. Mrs. Nelson told the social worker she couldn't manage and was too apprehensive to resume her caregiving responsibilities.

IS THERE A BETTER WAY? HEALTH POLICY REFORM

Chronic medical conditions generally progress in severity, are extremely common, and often are present in combination with other chronic conditions. With 88 percent of the elderly having one chronic condition and 70 percent having more than one, the Nelsons story is the rule, not the exception. The frequency of these problems forces one to ask: Why are health care dollars available for crises, not prevention? Interest in preventive strategies and models of health care that meet the needs of chronic conditions is growing, but still early in

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development. In particular, increasing concern about runaway health care costs has dampened enthusiasm to make the required changes. Even though prevention, improved medical compliance, and reduced complications would save money, the savings are generally seen over the long term. Both private and public health care systems have been reluctant to make such long-term investments.

What role should government and health policy play in improving the care of chronic conditions? Here are some specific and important places to start:

- Develop information technology to make medical records accessible to the many physicians caring for the individual with complex chronic conditions. This will reduce both medical errors and costs.

- Promote preventive health services, including screening programs, education, counseling, and self-management training.

- Make care coordination and care management available for the chronically ill to facilitate continuity of care and patient adherence to the plan of care.

- Develop a panel of targeted supportive services that permit the disabled to remain in their homes, including basic transportation, shopping, and meal preparation, as well as home modifications for safety.

- Ensure adequate staffing and expertise for the treatment of chronic illness. Attract high-quality health professionals to this field and require basic training in the care of chronic conditions in medical school and graduate training programs.

- Develop a network of support for caregivers to preserve *their* emotional and physical health, thereby delaying the need for institutionalization of the person being cared for.

- Develop methods to measure aggregate savings—to both society and the individual—of improving care for chronic conditions. Budgeting for the short term will never do justice to the benefits of preventive strategies.

All chronic medical conditions have a common need for a continuum of health care services built on principles of prevention and patient-physician partnering. These basic principles remain important at every stage of illness and disability. Separation of the period of independent function from the period of functional impairment is artificial, yet that is exactly how we currently approach chronic illness care and long-term care. If our goal is to truly preserve function and self-esteem in the large segment of our society living with chronic illness, then we need to start by bringing long-term care into the mainstream of health care for chronic conditions. □

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