

Treating Disease Is No Substitute for Caring for the Ill

America's health-care system focuses on curing acute problems but does far too little to support patients with chronic maladies

<https://www.wsj.com/articles/treating-disease-is-no-substitute-for-caring-for-the-ill-11575047264>

By Arthur Kleinman

Nov. 29, 2019 12:07 pm ET

I still sometimes wake in terror, haunted by the nightmare of an episode almost 15 years ago when my wife Joan, who was suffering from Alzheimer's disease, accidentally locked herself in our bathroom. Not only had the disease robbed Joan of her reasoning, it had also left her functionally blind. Pounding on the door and screaming in fright, she couldn't follow the simple instructions that I kept repeating about how to unlock the heavy bathroom door—and short of breaking it down, I had no way to get to her. I tried to reassure her that a locksmith was on the way, but she grew increasingly distraught, falling to the floor and howling in misery. I slammed my body against the door and kicked the lock, to no avail. By the time the locksmith arrived, my wife was delirious with fear, frustration and fatigue. And I was broken, realizing there was nothing I could do to make life right again.

Over my years of caregiving for Joan, I often felt frustrated and defeated—both by periodic emergencies like that nightmarish episode and the everyday work of care. Taken together, the drone of the mundane and the blast of the frenetic constitute the work of managing chronic disorders and disabilities, including the illness experiences associated with catastrophes such as Alzheimer's. Through my work as a psychiatrist, medical anthropologist and teacher, I was fairly familiar with the workings of our health-care system, but not until I became one of the estimated 40-50 million Americans acting as family caregivers did I understand the tragic

inadequacies of America's system for providing care for the chronically ill.

The U.S., in effect, has two health systems. One addresses *disease*, the science of what makes us sick; the other addresses *illness*, the human experience of being sick. Disease demands treatment, while illness calls out for care.

When people argue about health care these days, the system they debate is almost always that of disease—the medical diagnoses, the high-tech tests, the medications, the surgeries and the other interventions to treat serious injury or acute pathology. When hospitals and providers evaluate their success or quality, they reflexively do so in terms of medical outcomes and economic efficiency. The only factors that count in the provision of health care are those that can be enumerated and measured.

But the other face of American health care, one often hidden in the shadows, is illness: the patient's lived experience of pain and disability, suffering and symptoms, and the management of that experience by them and their families—often facing conditions for which there is no pharmacological or surgical “fix.” The course of many cancers, neurodegenerative diseases, severe depression, permanent disability and chronic conditions such as asthma, arthritis, heart disease and diabetes is nonlinear and unpredictable, calling on the resources of the sufferer and their caregivers to remain vigilant and agile, constantly struggling to adapt to changing circumstances.

We measure success in the treatment of disease in quantitative terms: We rely on machines that monitor bodily rhythms, check pathology results, enumerate the number of hospital beds occupied, measure time spent in emergency services and evaluate bills to health insurers. By contrast, on the rare occasions that we try to measure success in the management of illness, we do so in qualitative terms. We look for empathy,

compassion, communication, responsiveness, emotional support and affirmation—in short, whether caregivers are truly present for the patient. Do they seek to understand the patient’s experience or treat him or her as a task to be completed, a set of measures to be checked, a medical record to be filled in and questions to be answered as cursorily as possible? Our discussions of quality in health care too often exclude or minimize the fundamentally human dimension of care.

Health services and hospitals—even when they survey patients’ and families’ experiences—are overwhelmingly likely to focus on aspects that can most easily be measured, recorded, analyzed and presented to their governing boards and government regulators. For the tens of millions of Americans coping with chronic or terminal illnesses, the assessments that we perform and the concern that we convey are painfully inadequate.

Patients and their families—and the doctors and nurses caring for them—too often cope with long waits, poor communication, the acquired indifference of overworked and stressed-out staff members, the cynicism born of inadequate resources and unrealistic expectations, and the patients’ and loved ones’ bewilderment over how to navigate a chaotic, indifferent and bureaucratic system. This is health care without caregiving. My own family’s journey began in the disease-oriented medical system, where Joan and I sought a clear diagnosis from countless experts, each one of whom remains as faceless to me now as we surely were to them. Half of them rarely, if ever, seemed to make eye contact, poring instead over the medical records and test results in front of them or lost in the glare of their computer screens.

When Joan’s Alzheimer’s was finally identified, we passed fitfully into the illness system, which we found lacking in altogether

different ways. When the possibility of treatment gave way to the necessities of care, we had no medical specialists able or willing to help us make the transition—no one to tell us what we might expect, how we might prepare or even what kind of help we might need. No expert took the time to learn about Joan’s life, and our life together, so we might make the most of whatever time remained. Like so many others grappling with a chronic illness, we were simply handed a diagnosis, had some treatment options (or the lack thereof) explained to us, and sent off to figure out the rest of Joan’s life on our own.

America’s disease system is the subject of exhaustive and exhausting debate, but our illness system barely exists. For most, it is a fragile patchwork of beleaguered family members, friends and neighbors, overworked and underpaid home-health workers, and (with luck) perhaps some social workers or service organizations. Almost entirely dependent on our own instincts and resources, families like ours simply figure it out as we go: how to live a life disrupted by a disabling illness.

The debates now raging over health care miss the very real needs of both systems, but I worry most about how we can cope with the illness experience. We must rethink how we educate and evaluate health professionals. We must find the resources to elevate and compensate the dwindling ranks of home health workers. And we must build into the system support for the millions of family members whose determination and sacrifice sustain and enrich the lives of their loved ones. True health care must include care.

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