

Sounding Board

THE LONELINESS OF THE LONG-TERM CARE GIVER

I AM standing at a bank of phones, desperately punching in codes and numbers. Each time, the line goes dead. “Why can’t I get through to anyone?” I think. “I must be doing something wrong.”

I wake up. This time it’s only a dream. But the dream originated in a real experience. On the icy morning of January 15, 1990, my husband lay comatose in the emergency room of a community hospital after an automobile accident. Uninjured but dazed, I stood at a bank of hospital phones trying to reach people who could help me transfer him to a major medical center. I was unaware that, by a malevolent coincidence, most of the phones in the region were not working.

The dream recurs, and it has now taken on a new meaning. In the nine years since the accident, and especially in the eight years I have struggled to take care of my husband at home, I have frequently despaired: “Why can’t I get through to anyone?” Only in the past few years have I realized that I am not doing anything wrong. It is the health care system that is out of order.

Since I have spent 20 years as a professional in the fields of medical ethics and health policy, it is hardly surprising that I should reach such a conclusion. A recent series of articles in the *Journal* made clear the increasing fragmentation and inequities in the current market-driven health care economy.¹ But my personal experience as a family care giver has given me a different perspective. I see the health care system through everyday encounters with physicians, nurses, social workers, receptionists, vendors, ambulance drivers and dispatchers, administrators, home health aides, representatives of my managed-care company, and a host of other “providers.” The attitudes, behavior, and decisions of specific individuals make the system work or fail for me.

There are of course critical links between the behavior of individual persons and the system’s structural and financial incentives and rewards. Health policy makers and analysts rarely consider the impact of these incentives on the 25 million unpaid, “informal” care givers in the United States, who get little from the system in return for the estimated \$196 billion a year in labor they provide.² Family care givers are largely invisible, as individuals and as a labor force.

When my journey began, no one told me what to expect. There is no process of informed consent for family care givers. On that unforgettable January

day, I knew that I must ask, “Is my husband brain-dead?” And I knew what to do if the answer was yes. “No,” said the neurosurgeon at the community hospital, “but he has suffered a severe brain-stem injury. At his age [then 62] it is unlikely that he will survive.” The neurosurgeon at the medical center disagreed. “He will walk out of here 100 percent, but it will take some time.” “How long?” I asked. “Weeks,” he replied, “maybe months.”

My husband did survive, a testament to one of American medicine’s major successes — saving the lives of trauma patients. But he will never walk, and he is far from 100 percent. While he was in a coma, I read to him, played his favorite music, and showed him family pictures. After four months he gradually emerged from the coma, his thinking chaotic. After many more months of relearning basic words and concepts, he recovered many cognitive functions, and there were occasional flashes of his old intelligence and humor. But he is not the same person in any sense.

Although I worried most about his mental functioning, it is his body that has recovered least. He is totally disabled and requires 24-hour care. He is incontinent of bladder and bowel. He is quadriparetic, with mobility limited to the partial use of his left hand. (His right forearm was amputated as a result of an iatrogenic blood clot that failed to respond to surgery and drug treatment.) Even so, the most difficult aspect of his care is his changed personality and extreme emotional lability. Antipsychotic drugs now generally control his violent outbursts, but there are still unpredictable rages and periods of withdrawal.

As a rehabilitation inpatient he had physical therapy, occupational therapy, speech therapy, cognitive therapy, psychological counseling, nerve blocks, injections of botulinum toxin, hydrotherapy, recreational therapy, and therapeutic touch. He benefited to some degree, but nothing restored true function. He has undergone numerous operations, including placement of a shunt after a blood clot formed in his leg, tendon releases in both legs, removal of a kidney stone, and most recently, removal of a pituitary tumor. He has undergone oral surgery and extensive dental work.

During my nine-year odyssey, I stopped being a wife and became a family care giver. In the anxious weeks when my husband was in the intensive care unit, I was still a wife. Doctors and nurses informed me of each day’s progress or setbacks and treated me with kindness and concern. At some point, however, when he was no longer in immediate danger of dying, and as the specialists and superspecialists drifted out of the picture, I became invisible. Then, when the devastating and permanent extent of his disabilities became clear to clinicians, I became visible again.

At that point, I was important only as the manager and, it was expected, the hands-on provider of my

husband's care. In retrospect, I date my rite of passage into the role of family care giver to the first day of my husband's stay in a rehabilitation facility, a place I now think of as a boot camp for care givers. A nurse stuck my husband's soiled sweat pants under my nose and said, "Take these away. Laundry is your job." A woman whose husband had been at the same facility later told me the same story — different nurse. The nurse's underlying message, reinforced by many others, was that my life from now on would consist of performing an unrelieved series of nasty chores.

The social worker assigned to my husband's case had one goal: discharge. I was labeled a "selfish wife," since I refused to take him home without home care. "Get real," the social worker said. "Nobody will pay for home care. You have to quit your job and 'spend down' to get on Medicaid." Eventually I got the home care I needed — temporarily. Despite a written agreement to pay for it, the insurance company later cut off the benefit retroactively, without informing me, leaving me with an \$8,000 bill from a home care agency. The agency, which had failed to monitor its own billing, sued me. We settled for less.

When I brought my husband home, he had undiagnosed severe sleep apnea (which caused nighttime screaming), undiagnosed hearing loss, and poorly treated major depression. The first few months at home were nightmarish. Since the problems had not been diagnosed correctly, much less treated, I did not know where to turn. Yet a single home visit by a psychiatrist and a specially trained home care nurse, arranged by a sympathetic colleague who treats patients with cancer, gave me enough information, advice, and referrals to begin to master the situation.

In addition to holding a full-time job, I manage all my husband's care and daily activities. Being a care manager requires grit and persistence. It took me 10 days of increasingly insistent phone calls to get my managed-care company to replace my husband's dangerously unstable hospital bed. When the new bed finally arrived — without notice, in the evening, when there was no aide available to move him — it turned out to be the cheapest model, unsuitable for a patient in my husband's condition. In these all-too-frequent situations, I feel that I am challenging Goliath with a tiny pebble. More often than not, Goliath just puts me on hold.

Being a care manager also takes money. I now pay for a daytime home care aide and serve as the night nurse myself. My husband's initial hospitalization and rehabilitation were paid for by his employer-based indemnity insurance plan. He is now covered by my employer-based managed-care company, which pays for hospital and doctors' bills and, with a \$10 copayment, for prescription medicines. Home care aides, disposable supplies, and most forms of therapy are not covered, because they are "not medically necessary." My husband recently needed a new cus-

tomized wheelchair, which cost \$3,700; the managed-care company paid \$500. Medicare, his secondary payer, has so far rejected all claims. No one advocates on my husband's behalf except me; no one advocates on my behalf, not even me.

I feel abandoned by a health care system that commits resources and rewards to rescuing the injured and ill but then consigns such patients and their families to the black hole of chronic "custodial" care. I accept responsibility for my husband's care. Love and devotion are the most powerful motives, but there are legal and financial obligations as well. My income would be counted toward his eligibility for Medicaid, should we ever come to that.

The broader issue of a family's moral responsibility to provide or pay for care is much more complex.³ Why should families be responsible for providing such demanding, intensive care? Should this be a social responsibility? American society places a high value on personal and family responsibility. The thin veneer of consensus that supported some sense of communal responsibility in the past is cracking. This is not a uniquely American problem, however. Even with national health insurance, Australian, Canadian, and British care givers report similar problems of isolation and unmet financial and other needs.⁴ Only the Scandinavian countries assume that the community as a whole is primarily responsible for long-term care. Even so, the Swedish Social Services Act specifies some spousal responsibility.⁵

Widely held concepts of family responsibility derive from religious teachings, cultural traditions, community expectations, emotional bonds, or gratitude for past acts. Care givers rarely sort out their mixed feelings. From a policy perspective, there are historical antecedents and financial realities that encourage looking first to families for care. Perhaps the most important justification is that most families, or some members, want this responsibility. Many derive spiritual or psychological rewards from care giving. Taking care of each other comes with being a family. This is an especially strong value among recent immigrants or tightly knit ethnic communities who distrust the formal system but who often have too few resources to cope on their own.

The problem is not that public policy looks first to families but that it generally looks only to families and fails to support those who accept responsibility. The availability of family care givers does not absolve policy makers of their own responsibility to make sure that their actions assist rather than destroy families. Family members should not be held to a level of moral or legal responsibility that entails jeopardizing their own health or well-being.

Given the complexity of the health care system, what changes would make a difference for family care givers? The automatic answer tends to be: Whatever they are, we can't afford them. Or, whatever we

can afford is not worth doing. Many family care givers have serious financial problems. Nevertheless, a single-minded focus on money, based on an unsubstantiated assumption that most care givers want to be replaced by paid help, diverts attention from other critical needs.

The reaction to the Clinton administration's January proposal for assistance for the elderly and family care givers is an instructive example of the differing worldviews of health policy analysts and family care givers. Most professionals focused on the proposed tax credit of \$1,000 and found it wanting. The credit would not apply to people who pay no taxes, nor would it make a dent in the heavy costs of full-time paid care. The proposal does not do anything to create a coherent long-term care policy.⁶ All these observations are true. On the other hand, family care givers and organizations that represent their interests have been largely positive about the proposal. The tax credit is a tangible benefit that will help many middle-class families. Equally important, the proposal puts family care giving on the national agenda and gives states money and incentives to develop resource centers. These points are also all true.⁷

In my professional role, I know that much more is needed, including a restructuring of Medicare to better meet the long-term needs of the elderly and disabled and the creation of a more flexible range of options for home and community-based care.⁸ I also know that change will take a long time and will be determined by the interests of the major players and by political considerations. As a family care giver, I will take whatever help I can get when I need it, and that is right now.

Clinicians as well as policy makers have responsibilities toward family care givers. Care givers say they want better communication with professionals, education and training, emotional support, and advocacy to obtain needed services for their relatives and themselves. They want help in negotiating the impenetrable thicket of financing mechanisms, the frequent denials of services or reimbursements, and the inconsistent interpretations of policies and eligibility. They want respite, too, but through services that they can tailor to their needs. These are modest requests — too modest, perhaps — but unfulfilled nonetheless.

Care givers in the focus groups convened by the United Hospital Fund's Families and Health Care Project reported a lack of basic information about the patient's diagnosis, prognosis, and treatment plan, the side effects of the patient's medication, the symptoms to watch for at home, and whom to call when problems occur.⁹ Sometimes care givers reported that they were given conflicting information.

Managed care did not create this problem, but it seems to have exacerbated it. Often, professionals convey information in such a hurried, technical way that anxious care givers cannot absorb it. Hospital

staff members may assume, erroneously, that a home care agency will instruct the care giver. There are costs to these lapses. Failures in communication can lead to serious problems with the care of patients, including unnecessary hospital readmissions. Some families, however, become experts on the conditions of their relatives and the specifics of their care. Yet professionals frequently ignore this expertise, because it comes from laypersons.

Family care givers also want to be involved in decision making that affects the patient and themselves. Elsewhere, Connie Zuckerman and I have described some of the reasons clinicians have difficulties with family members, especially with respect to decisions about acute care.¹⁰ In my husband's case, I alone made the only important decision, which was to transfer my husband to a medical center on the day of the accident. After that there were never any clear-cut decisions, no discussions about the goals of care, and certainly no long-term planning. Although I repeatedly asked to attend a team meeting to discuss his prognosis and care, I was never given that opportunity. Nor was there ever any follow-up at home, a common complaint among care givers.

Care givers want education and training that recognizes their emotional attachment to the patient. Professionals seldom appreciate how much fear and anxiety complicate the learning of new tasks. Learning how to operate a feeding tube or change a dressing or inject a medication is hard enough for a layperson; care givers learn how to perform these procedures for the first time on a person they love. Fearful of making a mistake or simply upset by the idea of having to perform unaccustomed and unpleasant tasks, care givers may resist or fail, or persist at great emotional cost.

Months before my husband was ready to go home, a nurse insisted that I learn how to put on my husband's condom catheter. "I don't need to know this yet," I protested, "and besides, maybe he won't need it later." Ignoring our emotional state at the time, she forced me to do it (badly) until both my husband and I burst into tears. Later, when I complained to her supervisor, I was told, "We just wanted to break through your denial."

Families need emotional support. They frequently bring a patient home to a living space transformed by medical equipment and a family life constrained by illness. Privacy is a luxury. Every day must be planned to the minute. The intricate web of carefully organized care can unravel with one phone call from an aide who is ill, an ambulette service that does not show up, a doctor's office that cannot accommodate a wheelchair, an equipment company that does not have an emergency service. There are generally no extra hands to help out in a crisis and no experienced colleagues to ask for advice. Friends and even family members fade away.

Programs that train and support family care givers can be based in hospitals, community agencies, schools and colleges, home care agencies, managed-care companies, or other settings. The United Hospital Fund's Family Caregiving Grant Initiative is funding several such projects.

If family care givers need education, professionals need it just as much. Education for doctors, nurses, and social workers should include understanding the needs of family care givers. Ideally, all professionals should have the experience of seeing firsthand what is really involved in home care. In-service programs can educate health care professionals about family dynamics as well as build communication and negotiating skills.

Family care givers must be supported, because the health care system cannot exist without them. And there is another compelling reason: Care givers are at risk for mental and physical health problems themselves. Exhausted care givers may become care recipients, leading to a further, often preventable, drain on resources. Does my managed-care company realize, for instance, that during the past year it paid more for my stress-related medical problems than for my husband's medical care?

No single intervention will change the system, but small steps taken together can cover a long distance.

As I enter my 10th year as a family care giver, it is hard to believe I have come this far. Today is a reasonably good day. But what about tomorrow? And next week? Hello? Is anyone listening?

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REFERENCES

1. Angell M. The American health care system revisited — a new series. *N Engl J Med* 1999;340:48.
2. Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Aff (Millwood)* 1999;18(2):182-8.
3. Levine C. Home sweet hospital: the nature and limits of private responsibilities for home health care. *J Health Aging* (in press).
4. Schofield H, Booth S, Hermann H, Murphy B, Nankervis J, Singh B. Family caregivers: disability, illness and aging. St. Leonards, Australia: Allen & Unwin, 1998.
5. Barusch AS. Programming for family care of elderly dependents: mandates, incentives, and service rationing. *Soc Work* 1995;40:315-22.
6. Graham J. Halfway measures. *Chicago Tribune*. January 17, 1999.
7. Statement by Suzanne Mintz, President, National Family Caregivers Association, Kensington, Md., January 6, 1999.
8. Cassel CK, Besdine RW, Siegel LC. Restructuring Medicare for the next century: what will beneficiaries really need? *Health Aff (Millwood)* 1999;18(1):118-31.
9. Levine C. Rough crossings: family caregivers' odysseys through the health care system. New York: United Hospital Fund, 1998.
10. Levine C, Zuckerman C. The trouble with families: toward an ethic of accommodation. *Ann Intern Med* 1999;130:148-52.

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