

Care and TREMBLING

by Deborah Stone

Medicare's antifraud program and its stepped-up focus on home health care have created a climate of intimidation, fear, and guilt. Increasingly, paid caregivers feel that this climate contradicts their sense of common decency and morality, makes them feel like criminals for caring as they watch their clients get hurt by the system. What hurts them most is that they are forced to participate in this withdrawal of care. This discussion showcases the dangers of making caring work formal and public.

Until fairly recently, most caregiving was invisible to the public eye. Caring was done informally in the private sphere, mostly by women, for relatives, neighbors, and friends; and it was mostly unpaid. Gradually, over the course of the 20th century, caring has gone public. As middle-class women moved into the labor force, society responded by creating new entitlements to care for children, the sick and disabled, and the elderly. And as needs and entitlements expand, so does the provision of care.

Much care is now provided by people who care for a living and by professionals who gain their work identity from caring. Caring is the business of firms that care for profit, and of nonprofit agencies that care as a mission. And much care is now paid for by public subsidies, tax credits and

exemptions, and private and public insurance plans that tightly monitor and regulate the caregiving they fund.

When care goes public, there is a clash between the norms of caring in private relationships and the norms of efficiency, professionalism, and accountability in business and government. Care gets reframed as a problem of bottom lines and cost containment. This cost squeeze comes from private enterprise, of course, but also from the public sector: legislators slash caregiving budgets to calm taxpayers and Wall Street, just as executives pinch caregiving outlays to protect their shareholders and profits. Since medical professionals, government, and business all use standards to define quality, care tends to get standardized—and restricted to what fits into the boxes of printed forms. As care is reduced to instrumental tasks, human relationships can get lost, and caregiving can be depleted of its emotional force and spiritual meaning. Most troubling of all, when care is recast as an economic and bureaucratic good, deep norms about altruism, generosity, and cooperation are reshaped as well.

Though cost-containment pressures have shifted more caregiving out of hospitals and into homes, Medicare's home health budget was nonetheless slashed by the Balanced Budget Act of 1997 (BBA). For two years the federal government has been running a cloak-and-dagger antifraud initiative known—quite inaptly—as Operation Restore Trust. To find out how recent Medicare and managed care changes are affecting caregiving at the bedside, I have been interviewing home care workers in New England and observing one nonprofit home health care agency in depth.

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The more I talked with people, the more I saw how financial tightening and the ratcheting up of managerial scrutiny are changing the moral world of caregiving, along with the quantity and quality of care.

The Kindness of Strangers

Caregivers work under a constant moral burden. They cannot give enough to satisfy the needs they think people have or the care they think people deserve. Frequently, the rules of insurance plans or agencies prohibit them from doing what they think is right. Formal policies sometimes clash with what they understand to be the rules of ordinary human morality. When that happens, they are caught in a moral double bind, forced to violate one set of norms or rules in order to abide by another.

When care is provided by strangers instead of by family and friends, strange things happen. Some of the home care aides (HCA) I've talked with have pointed out the odd disparities between what they're allowed to do as certified and licensed paraprofessionals—in other words, as strangers—and what they're allowed to do as ordinary citizens, relatives, or friends. They can't give prescription medicines. They may dispense, apply, or feed any nonprescription lotions or potions, but they cannot even rub on a prescription cream for a client who can't reach her own feet or back. They are not allowed to pick up a person who falls, because they might cause more injury if the client sustained a fracture. Certified nursing assistants, as these HCAs are called, are required to work under the supervision of a registered nurse, and as these examples show, they must observe strict boundaries between medical and personal care. Meanwhile, any child, or any ignorant but well-meaning neighbor, friend, or relative, may dispense prescription medicine or help someone up from a fall.

If a client asks a certified aide to just sit and talk, the aide cannot comply, because she is there to do bodily care. If the client doesn't want any type of bodily care, such as a shower, shampoo, or fingernail cutting, one aide said, "I try to coax them into something, because ... in order for the agency to get paid, to pay me, I have to do some type of hands-on [care]." Of course, care providers usually do chat for a few minutes, because they understand how intrusive and demeaning needing help can be, and they know you can't just start doing tasks for people without establishing some kind of human connection. But they live with an undercurrent of tension between their clients' desires for company and companionship and the more instrumental care they are trained and paid to provide.

In some agencies, if a client asks an aide to do certain household chores, the aide is supposed to refuse. An aide in New York told researchers Ruth Glasser and Jeremy Brecher, "You're not going to do something that gets you in trouble, but sometimes the rules have to be bent a little bit.... Like,

for example, we're not allowed to get up on ladders and change curtains. But sometimes you have clients who don't have a relative or somebody to come over and do it, and if you think you're capable of doing it, you do it." When caregivers are asked for kinds of help they aren't supposed to give, they have to negotiate between their job definitions and their personal assessments of the care they think people want and need.

When I asked aides to tell me how they know when they have done a good job, they almost always say something like, "The client smiled," or "The client is all pretty and looks nice—you've made her happy," or "They say, 'Thank you.'" When I asked one aide to tell me about a time she felt she gave really good care, she replied, "It always makes you feel good when somebody says, 'I'm really glad to see you. I haven't seen anybody all day.' And you know you're bringing a little spark in to them." They talk about how rewarding it is to make a difference—client happiness is their barometer.

They still love their work, but more and more often they are having to watch their clients get hurt by the system. And they are forced to participate in the withdrawal of care.

Some aides told me that Medicare clients often ask them to continue care on weekends or on a private basis after the agency discharges them. The clients would love to keep the same aide, and often the aides have grown very fond of a client and would love to continue caring. But the agency maintains separate staffs for Medicare and non-Medicare clients, and aides are keenly aware that if they went to someone's home on a private basis, they wouldn't have workers' compensation or any benefits, and they would be open to suits if a client or family became disgruntled with their work.

Once they are paid and licensed, caregivers' concept of caring work changes abruptly. They now think of caring work as something for which they need the benefits and legal liability protections that people expect in paid jobs but don't even think about when caring for friends and relatives. For their part, agency managers understand and regret the disruption in caring relationships when the division of labor is determined by the client's funding source. But if the agency were to allow more fluidity between its divisions, or between its services and its aides' private-duty services, it would engender suspicion that it was playing fast and loose with Medicare rules.

Also, when caregiving becomes formalized, it is controlled by someone who is neither the caregiver nor the cared for—it is no longer a matter of private obligations and gifts, personal affection and tiny personal struggles. Once a business or government agency gets involved, it has interests, concerns, rules, laws, and reputations to worry about.

Bureaucracies of Care

When organizations provide care as their *raison d'être*—whether they are for-profit firms, nonprofit agencies, or private or public financing programs—they must be concerned with things other than the people getting and giving the care. They must pay attention to productivity, costs, waste, fraud, and solvency. They must worry about pleasing their shareholders, boards of directors, bill payers, insurance companies, Medicare and Medicaid offices, auditors, accrediting agencies, and Congressional oversight committees. All of the sudden, the goals of staying in business, balancing the books, and lowering costs displace the goals of making patients feel cared for and improving their well-being.

This new reality reflects three distinct trends. First, with more women in the paid labor force—either out of choice or economic necessity—fewer are available to do the traditional woman's unpaid work of caregiving. And fewer extended families live in close proximity to one another, which makes it even harder for relatives, male or female, to be caregivers. Second, society has created a partial entitlement to paid caregiving by strangers. And third, this entitlement has given rise to severe cost-containment pressures that in turn intensify the bureaucratization. All of these dilemmas would arise in any system that shifted from unpaid to paid caregiving. But the contradictions surely would be less acute if there were more adequate financing and more respect for the caregivers' professionalism. Greater subsidies for paid family leave would help, too, so that more care could be done according to traditional norms but without economic sacrifice.

Sitting in on case conferences, I'm struck by how much talk there is of goals: "What are our goals here?" is the question about every case. Even more surprising is the most common answer: "Our goal is to be out by the end of the week," or "to be out by the end of the month." With the BBA's drastic cutbacks for home health care, and managed care's stringency as well, agencies seem to have had to shift their goals from providing care to terminating care. They can't provide care if they don't stay in business, and they can't stay in business on lower revenues unless they terminate unreimbursed care. Cost control, then, introduces a perverse logic.

If the focus on goals shows up in an emphasis on time frames and "getting out" of the client's home, it also shows up in the content of caregiving. Short-term goals and long-term goals must be defined and documented. Nurses and

physical therapists tell me their care has had to become much more narrowly focused in the last few years. They have had to document a specific medical problem for each patient, such as an unhealed wound or a knee injury, and they're not supposed to spend any time addressing other problems—even other medical problems—that are not listed as the reason for needing home care.

Caregivers also have to document patients' progress toward goals. If the reason for care is an unhealed wound, nurses must write down a date when the wound is going to heal. "This is such a crap-shoot," said one nurse. "Would you mind telling me how in hell I'm gonna know when this wound's going to heal?" She and other nurses said they feel they are allowed much less time to teach patients how to care for themselves. They are allowed time to explain something only once—even if the patient forgets or needs more explanation. "Prior to all this push and shove," one nurse said, "[teaching] was more tracked in the patient's learning capacity. You didn't feel like if you told them something, whether they got it or not you just wrote down you told it to them."

Medicare requires that patients show progress toward their goals in order to remain eligible for services. In team conferences, I heard a fair amount of talk about patients who "weren't progressing" toward their goals, always followed by some discussion of whether there were legitimate reasons for this lack of progress, or whether it was a matter of what the caregivers call "noncompliance." The agency has to cover itself with Medicare, so the caregivers are forced into making uncomfortable judgments. Do they find a way of showing progress to protect patients' eligibility? Do they abandon patients who they feel are to blame for their own lack of progress? Should they be in the business of judging patients and assigning blame in the first place?

When ordinary people care for their own family members, they don't think about progressing toward goals. They think about their relationship. And if you ask them to articulate their goals, they are likely to say that they want to make their relatives as happy and as comfortable as they can, and preserve their dignity. This is especially true in the case of adult daughters caring for parents. Historian Emily Abel, author of *Who Cares for the Elderly?*, found that adult daughters are overwhelmingly concerned with reciprocating the care they received as children, but without reversing roles in a way that demeans their parent. They're acutely aware of how hard it is for a parent to be cared for *like* a child, *by* a child.

In the private sphere, the goal of home health care, if we were to put it in these terms, might be to express love and gratitude, and to preserve identity and meaningful relationships in the face of one person's decline. In the public sphere, the imperatives of organizational survival displace these private purposes and motivations for caregiving. Yet the caregivers still care, and they care intensely; the emotions and the attachments are not diminished.

The main strategy of keeping costs down in home health care is to limit care to medical needs and medically related tasks and to eliminate any care that is merely social. Medicare and most of the insurance companies will now pay only for skilled medical services and for care that is necessary to cure a medical problem. In a case conference, I heard about a woman who was just home from a rehabilitation center after an accident that left her paralyzed from the neck down. She and her husband, who was caring for her full time, were overwhelmed with the problems of how to cope with everything from her bowels, to getting her from bed to wheelchair, to running their business. They'd already used up the three home health care visits their insurance company had allowed. When the agency called to get more visits authorized, the insurer at first refused, saying her medical condition was not stable. All their difficulties were only "emotional adjustment problems."

How Caregivers Cope

Payors, naturally, use the medical/social distinction as a way of limiting their expenditures. But agencies that provide caring services find it hard to sustain that distinction. As one aide put it, "You can't just go in and get out. I'm sorry. You know, my grandmother had people taking care of her.... I wouldn't want them to do the same—you know, just come in and wash her up and leave. They have to have some kind of relationship going." The caregivers are keenly aware that home health care is very intimate and very personal, and that it's very intrusive to have someone come into your home, much less touch your body. Caregivers must build rapport and trust before they can take care of their patients, and that's not just something that has to be done on the first few visits, when a client is new to home care. Making a social connection has to precede every episode of caregiving. "Even now," one aide said, "I still have patients that'll say, 'Come sit down and let's talk for a few minutes.' You know, they don't want to get right to business; they want to visit for a few minutes."

The line between medical and social, emotional, or spiritual evaporates in practice. Yet because both public and private payors use this line to try to manage their costs, agencies and individual caregivers are pressured into pretending they don't cross it. They joke about how they treat other problems in addition to the official reason for care, and they even sometimes care for other members of a patient's family. Good care often requires observing a patient's spouse and attending to his or her health problems as well, for the spouse is often the caregiver when the agency people aren't around. The agency caregivers know what not to write down, and they are frustrated by payors' blindness to the realities of human life.

Virtually all direct care providers I have talked with—all the nurses, physical and occupational therapists, and HCAs—

say they've visited clients on their days off. They consider it normal, and when I ask about this practice, they tell me, "Oh, everybody does it." One woman said, "I have on occasion run into somebody's home when I wasn't treating the person. Or, we are treating but I wasn't normally going." I asked what she did on these occasions. She said she never gave a treatment, but she would just check on how someone was doing. "But I think that's called being a neighbor."

It is also, in effect, a subsidy from the caregiver's scarce free time. Caregiving bureaucracies are betting that the caregivers will dip into the well of their own humanity to offset the budget constraints and the stifling rulebooks.

Because Medicare, the largest payor of home care services, is currently scrutinizing and cutting back home care services, many long-term clients are in jeopardy of losing their home care benefits. Other insurance plans are tightening up as well. Increasingly, caregivers feel that insurance rules contradict their own sense of common decency and morality. Visiting clients on their time off becomes a form of resistance to new insurance rules—a form of protest.

When team members heard about the quadriplegic woman mentioned earlier, one nurse burst out: "Well, I'll just go visit her *as a friend*. And if I happen to have a few little things in my pocket...." Another team member chimed in, "Yeah, I told her I go to the market all the time, and if she needs anything, she should give me her list." A couple of different caregivers told me about a patient with a chronic crippling disease who'd been getting home care for 10 years, but who they feared was going to be cut off by Medicare. One of his aides told me she had reassured him, "'Hey, if they cut you off, you won't go without a bath.'... I told him I'd stop after work and do it. They can't stop you on your own time. After 3:30, you're a private citizen."

Though agencies and their staff are under tremendous pressure to cut back the formal, reimbursed care they provide, nobody, as far as I can tell, is stopping caregivers from voluntarily picking up the slack. Aides and nurses tell me that the agency discourages them from getting too emotionally attached, but they get attached anyway. "You can't help it," they say. "If you're human," or "if you have any human compassion, you just do." The case managers and supervisors know this. They know that nurses and aides sometimes accept phone calls at home from their patients, even though they're not supposed to give out their numbers. They know that nurses and aides often visit clients on their days off and do special favors, even though they're not supposed to. The supervisors, who are nurses themselves, look the other way. They've been there.

Of course, everybody—taxpayers, insurance companies, agencies—benefits from the free, volunteer labor that caregivers provide when they do it on their own nickel. No doubt, supervisors and managers don't actively discourage this sort of thing, because it helps keep their clients happy at lower costs. But they also know the staff will do it anyway,

and to a large extent, they share the direct caregivers' moral commitments. In this sense, the exploitation of women's generosity that characterized traditional, informal caregiving systems continues in the new systems of formal, socially financed care.

Compassion and Suspicion

The caregivers talk about their personal attachments to clients and their "extras" as though their deep affection, fierce loyalty, and overflowing generosity were somehow illicit. When I asked about ways they go beyond their duties, some of them, especially the aides, lowered their voices to a whisper. Some got visibly uncomfortable. They all said something to the effect that "the agency discourages" getting emotionally involved and doing things outside the job description or outside the care plan.

Several aides said they sometimes pick up mail, bread, or other items for a client. Such favors are against the agency's rules, but I didn't know this the first time an aide mentioned it. I only figured it out when she hesitated to talk about it and when I realized she was trying to justify herself to me. The man lives three miles from the store, she told me, and his daughter lives even farther away in a neighboring town. "It's very inconvenient for her to bring him milk. So how's he going to get milk? How's he going to get a loaf of bread? I'm going right by. It's on my way home." She then asked, "How can you say no? You can't. You're a human being. I go out of my way to do things for people.... I guess I'm guilty."

She used the word "guilty" three times when talking about her favors and kindnesses. Finally I asked her, "You're doing something nice for these people. Why should you feel guilty?" "They tell you you're not supposed to have contacts with patients outside of work," she answered.

Medicare's antifraud program and its stepped-up eligibility reviews create a climate of intimidation, fear, and guilt. Several caregivers said they believed there has been abuse in the home care industry, and that sometimes perhaps they or their agencies have kept clients longer than they should have. But they all talked about how the new climate "makes you feel like a criminal." "Now you feel like you can't make a mistake—you're being watched," one physical therapist told me. With Medicare reviewing and questioning more and more cases, "you feel like a crook from the start," said another. "I feel that I'm shortshifting the patient," a nurse said about the speed-up in teaching. "We feel like we're abandoning our patients," another nurse said about Medicare's refusal to continue to pay for chronically ill patients. One nurse told me about a patient who benefits greatly from home care, but who, she thought, she was able to see only "because nobody's denied it yet. But I am feeling very guilty about it." They're waiting for the ax to drop on their patients—and meanwhile, they're feeling guilty for caring.

These are women who overwhelmingly love their work. Almost all of them volunteered that they find their work incredibly rewarding, and that they wouldn't want to do any other kind of work. When I asked explicitly how cutbacks have affected them, a few mentioned reduced client loads and working hours, but almost all of them used the word "sad." They still love their work, but more and more often they are having to watch their clients get hurt by the system. And they are forced to participate in the withdrawal of care.

Paradoxically, public accountability has brought moral confusion to the world of care. When people care in a public context as employees of an agency and, in effect, as agents of insurance companies or Medicare and Medicaid, they are made to feel that their personal relationships with clients are illegitimate—something to be hidden, kept in check, restrained, best left unspoken. Not only their professional judgment but their compassion comes under suspicion. They talk about caring and their caregiving work almost as if they were engaging in civil disobedience. They frequently justify themselves by using the terms "human," "friend," or "citizen" and insisting that insurance or agency rules shouldn't prevent them from doing what *any* human being or *any* citizen would and could do.

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these are the real dangers of making caring work formal and public. We are in a political time when a mean spirit dominates our public philosophy, and an obsession with cost control dominates our public policy. When these values infuse the work worlds of people who care for a living, they may become all citizens' way of seeing what is morally proper in their relations with fellow citizens. When empathy, generosity, and reaching out to your fellow human beings are perceived as civil disobedience, we are a society in trouble.

In grappling with the issue of long-term care for the elderly and chronically ill, most politicians and policy analysts have worried primarily about one danger—that if public programs pay for long-term care, they will displace much of the voluntary care currently offered. They worry that public responsibility for long-term care will erode family responsibility and that hordes of people will crawl out of the woodwork to devour any new care that is subsidized by public funds or private insurance.

Policymakers ought to worry instead about a different kind of displacement: the displacement of caring relationships and social connections by narrow, task-oriented bodily maintenance, the displacement of empathy and affection

by cool professionalism and calculated fiscal prudence, and the displacement of an ethic of responsibility for one's neighbors by an ethic of working-to-rule.

If we care about preserving the norms of reciprocity, trust, and mutual aid that make us a community, we had better take better care of our caring work. The solution to these dilemmas is not to shove caregiving back into the invisible world of women's unpaid, unacknowledged work. Instead, we need to look into the heart of caregiving, to remind ourselves what we truly value. Before we can have intelligent conversations about how much to socialize the costs of caregiving—how much for paid family leave, how much for paid professional care—we need first to decide that humane caring matters. □

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