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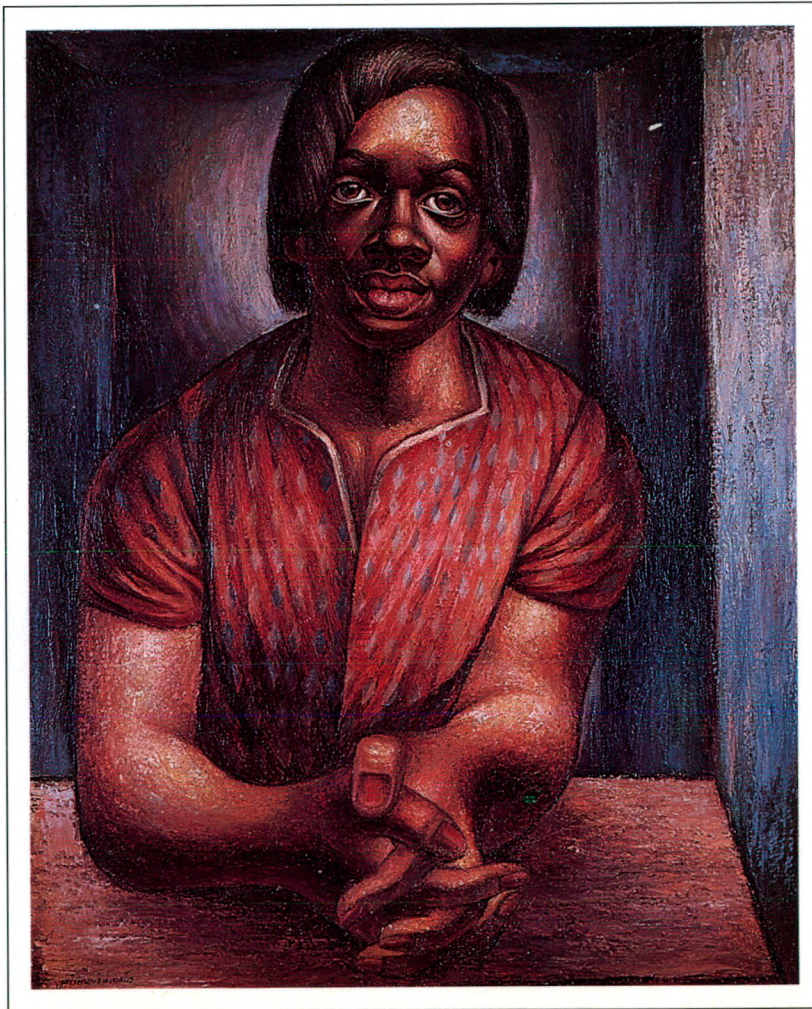
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SECOND OPINION

HEALTH • FAITH • ETHICS



Chronic Dependency and Caregiving • Narrative Ethics • Selling and Donating Organs

A publication of the Park Ridge Center for the Study of Health, Faith, and Ethics

COVER

Woman Worker. Oil on canvas by Charles White, 1951.

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S E C O N D
O P I N I O N

HEALTH • FAITH • ETHICS



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The Park Ridge Center exists to explore the relationships among health, faith, and ethics. In its programs of research, publishing, and education, the Center gives special attention to the bearing of religious beliefs on questions that confront people as they search for health and encounter illness. It also seeks to contribute to ethical reflection on a wide range of health-related issues. In this work the Center collaborates with representatives from diverse cultures, religious communities, health care fields, and academic disciplines and disseminates its findings to professionals and others interested in health, religion, and ethics.

Second Opinion, as its name implies, recognizes that the complexities of modern health care make it increasingly difficult to find the single “correct” action, thought, or method. Each situation is open to a variety of apparently legitimate and appropriate interpretations and applications. But such confrontations with ambiguity need not lead to discouragement. They can instead elicit greater research, discussion, and thought.

By inviting contributions from a wide range of perspectives, *Second Opinion* stimulates interdisciplinary conversations between members of fields relating to health, faith, and ethics. While other publications deal with one or two of these concerns, *Second Opinion* distinctively seeks to address all three. The Park Ridge Center created this publication in the hope that it will help form one public out of a number of related constituencies. This public will not only wish to relate ethics and faith to health issues, but should also, through lively and enlightened interchange, be better equipped to do so.

SECOND OPINION

Volume 19, number 2* • October 1993

A publication of The Park Ridge Center for the Study of Health, Faith, and Ethics

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INITIAL COMMENT

The Chronic

"CHRONIC DEPENDENCY AND CAREGIVING" heads the brief listing of topics on the cover of this issue of *Second Opinion*. Since *chronic* involves simply *chronos*, "time," one would expect its uses to be neutral. But pondering the word during the time that we worked on this issue and choosing to look it up in the dictionary, I found that it almost always has unpleasant connotations. The *Oxford English Dictionary* does give the neutral definition "of or relating to time; chronological" first, but marks it *Obsolete*. For the rest, the defining has to do with "of diseases, etc.: Lasting a long time, long-continued, lingering, inveterate; opposed to *acute*." "So with *invalid*, and the like."

Interested as we are in the health-faith-ethics nexus, scholars at the Park Ridge Center have to pay much attention to "the chronic." We know that not only matters of ethics but also those that concern the search for meaning, the interpretation of suffering, the summoning of resources for coping and caring alike—all demand special reserves of energy, dedication, and reflection. We hope that our address to these "lasting-a-long-time" concerns will be of help to all those who would address human need.

A major portion of the issue is devoted to the problem of chronic care treated by Debbie Ward in "Women and the Work of Caring." In this construction the word seems to carry a positive connotation: everyone speaks well of "care." Yet

as one reads on, it becomes clear that dealing with the chronically ill is a service society does not honor with sufficient pay, status, or understanding. In an interview, nursing assistant Joyce Blackwell picks up on Ward's reference to the chronic low pay and frustration that go with the "women's work" of chronic care, and Claudia George considers the issue from the viewpoint of a family member seeking to give respectful care in a chronic situation. Gloria Miller begins where those two respondents do but suggests alternatives by referring to a California program, On Lok Senior Health Services.

Still replying to Debbie Ward, Frances Leonard calls attention to demographic trends that will reduce the ranks of family caregivers available to provide long-term care; she also thinks that religious motivations have often functioned negatively, furthering exploitation of those giving care. (This article shows once again that accenting "faith" does not always mean for us "good faith," successful strategies, or the best results.) Then, to liven things up, Raymond J. Lawrence, Jr., checks in from a man's (not "*the men's*") point of view. His purpose is to isolate a gender perspective that he thinks will not go far in solving the problems of chronic care and to suggest a more proper focus on economics.

Notice how the concept of *chronic*, openly mentioned or implied, runs through other pieces

as well. Courtney S. Campbell speaks in line one of “a chronic shortage” in the supply of transplantable organs. He would not speak of “a chronic supply.” But there is a positive cast to his conclusion, where he speaks of “the gift model” of procuring organs, which he believes expresses “a richer account of human beings and human relationships” than does an organ market.

Charles J. Dougherty does not use the word but attributes to the Uniform Anatomical Gift Act a failure that we could call chronic, a failure to achieve good results. So we have “chronic failure” to add to the list, but the author does not leave us there. His positive twist involves recognizing the family or the immediate social context of people to a greater degree than current law requires.

In “Voices,” Tod S. Chambers gathers the recollections of several caregivers who worked with the same patient, a man who had suffered a stroke. The narrative points implicitly to the chronically difficult circumstance addressed by Debbie Ward and her respondents—when a person’s wish to be cared for at home places demands on the family that may be simply too large to be met. Kathryn Montgomery Hunter and Steven H. Miles (whose capable editorship of the Case Stories section concludes with this tenth in the series) then readdress the whole concept of “narrative ethics,” the telling of “the whole story.”

C. Bryant and Mark D. Fox further exemplify the narrative mode. Bryant draws from the deliberations of a hospital ethics committee in constructing a fictional account of a patient who “couldn’t remember a time when he didn’t want to die,” and Fox juxtaposes clinical and personal modes as he tries to incorporate a fellow medical student’s illness and death into his understanding of the healing art.

Now, at last, we deal with the purely positive connotations of *chronos*. For one basic feature of the story is that it moves through time. Narrative ethics intends to address all kinds of issues, including those having to do with chronic disease and chronic care through the passages of life and time. It does not produce cures, but it helps us decide what is good in relation to care, and it assists those who care in their own attempts to make sense of “the whole story,” of which disease is only a part.



Martin E. Marty



Beckie King. Pencil on paper by Andrew Wyeth, 1946.

Collection of the Dallas Museum of Art. Gift of Everett L. DeGolyer.

Women and the Work of Caring

Debbie Ward

I STARTED MY LIFE IN HEALTH CARE as a home health aide. This means I worked in households as a nurses' aide, supervised by the visiting nurse. I helped people bathe, I cooked breakfast, I tidied up piles of old *National Geographics*. I worked in one home where I broiled, for the only time before or since, two-inch-thick lamb chops and in another home where 20 cats guarded the sickroom without benefit of litter boxes, just a growing mulch of sodden and fouled newspaper on the kitchen floor. I worked in a home where the aged auntie gave me a copy of *The Life of a Perfect Woman* and in another where the naked, stooped, cachectic patriarch said to me, as I held him upright in the shower, "Don't you think my body is like that of a Greek god?"

Like other college graduates in the 1960s I was high of hope and low of marketability when I wandered into a gray frame house in Cornwall Bridge, Connecticut, with a sign outside that read Housatonic Homemaker Home Health Aide Association. I am telling the truth when I admit that

I thought this was a place where I would find suggestions on safe canning techniques and how to dry fruit. I was thinking of the agricultural extension office. Instead I found a community service agency looking for likely candidates to become home health aides. I needed a job, having left gainful employment in the big city to start life in the country. My partner was soon to become a janitor in a nursing home. (Years later, we hit our collective foreheads and wondered why he didn't become a home health aide, too. But this was 1971, and our gender boundaries were dated.) With two weeks' training at the hands of the State of Connecticut in topics ranging from giving a bath to coping with the demented patient, I was sent out on what would develop into my lifelong career interest—the caregiving work of women.

The first home to which I was assigned was a scene from *Great Expectations*. The cirrhotic matriarch lay dying in the dining room, the table replaced by her bed of pain. In the kitchen, the evil daughters fought over parts of the soon-to-be estate. The public health nurse took all this in, as she knew I did, while she enlisted me to wash and turn the patient, care for her lips and gums, apply lotion to her fragile skin, and wait. This I did for about three

Debbie Ward is an assistant professor of nursing, Community Health Care Systems Department, School of Nursing, University of Washington, Seattle.

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four-hour shifts of work, until one afternoon, the nurse called me at home to say, "Our patient died this morning. You will be getting a new assignment." And so I did, many of them, for three years before I started nursing school.

I have had many opportunities, before and since my days as a home health aide, to think about and perform the work of caring. I tended dolls, dogs, and horses, and closely observed the birthing of too many cats. I cowered while acting as nurses' aide to my mother, who tended my critically ill father during a neurologic infection that serially paralyzed his cranial nerves before being arrested by then-miraculous steroids. As a student nurse, I cared for patients in childbirth, for patients before and after surgery, and for psychotic adolescents on a locked ward. I went out into the community to see people in their own homes. I went to see why a toddler wasn't gaining weight and found that in the crush of 17 people in the home, he couldn't get to the food. I went to see a woman post-heart attack and found her husband most worried about the state of his lawn, which had been neglected during her hospitalization. As a nurse practitioner in an inner-city clinic, I made house calls on a lady too weak to make it down and up the four flights of stairs in her housing project, and on another carefully saving all her garbage.

Later, I took the point of view of a researcher. For my doctoral dissertation in health policy, I calculated a value for the time unpaid caregivers spent caring for frail elderly friends and family members. Using data from the 1982 Informal Caregivers Survey from the National Center for Health Statistics and Research, I found the value of one year's caregiving to frail elderly ranged from 9 to 17.5 billion dollars, depending on the valuation

method used (Ward 1987). I suggested that this figure represented a massive subsidy, paid largely by women, to the national welfare. A few years later, I conducted intensive interviews with a small sample of low-income women caring for chronically ill elders in their homes and, with a doctoral student colleague, analyzed their stories of making do (Ward and Carney 1992).

What I've read, but especially what I've seen and studied, leads me to believe we face an enormous

need—providing supportive chronic care to our fellow citizens—that calls for more than fiscal and structural change, hard enough in themselves to come by. In addition to committing funds and implementing programs, we will be called upon to question our beliefs about *who* should take care. Women? Women at home? Women of color in homes not their own? A basic tenet of U.S. political culture—

rugged individualism—will be shaken by such questioning, and beliefs about family responsibility—that families should care for their own—will be laid bare. Hard questions will be posed as the citizenry considers long-term care: Who will pay? and How much will it cost? But other, less easily categorized questions will be hard, too. Who is responsible for the frail and dependent among us? Can we assign enough dignity to the homey tasks of supportive care to make them competitive with other demands, such as success and promotion in a paid job? Will the private sector guarantee long-term care for all? Could the public sector assume the responsibility of chronic care? Can tending become gender-free? May women express their desires not to provide care without being accused of familial treason? Can men provide care without paying a price for breaking out of gender stereotypes?

In this essay I address four questions basic to all

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the above: Who needs chronic care? What do they need? How does it get done? And what are the consequences of the status quo?

Who Needs Chronic Care?

THE ELDERLY. Everyone nods in recognition, but no one is too excited by the demographic revolution of aging. When asked why nurses don't want jobs in long-term care, my undergraduate students respond, "Because they fear death." This is more than pop psychology or a line they learned from the movie *Moonstruck*. The impulse to turn away from impending decline is widespread, despite (or because of) the facts in our face. Not only are individuals living longer, but the population as a whole is aging. The Census Bureau projects that by 2025, the over-65 population will double (Kovar 1986). The oldest old, persons over 85, are the fastest-growing segment of the U.S. population, and they are the most likely to require physical and psychosocial assistance (Rosenwaike 1985). My birth cohort—the cowcatcher on the baby boom train—is 20 years from retirement. We are the population bulge that will cost: pension costs, hospital costs, nursing home costs, retirement health-benefit costs (periodic warning tremors are loosed as corporations are forced to change accounting practices to include the real costs of impending retiree health benefits). These economic and political sequelae are still underappreciated. At the same time, the sociological sequelae are virtually ignored: what happens to households and community life with so many older people to assist? Even among severely disabled elderly, 79 percent are living in the community (Rivlin and Weiner 1988). Most elderly live at home, and the assistance they require comes not from paid workers in institutions or agencies but from kin caregivers, family members and friends, most of whom are women.

Not just the elderly need care. Consider chronically ill children, from those at home on breathing machines for their chronic respiratory disease to

children with fetal alcohol syndrome, going to school but needing a vigilant full-time supervisor. The adolescent with cystic fibrosis home sick for a week. Head-injured adults: a working guy on his own until his motorcycle accident, now with the dreaded label "soft neurological signs." He is unable to move through the sequential steps of a task, gets in fights at work, quits, and impulsively gets on the plane to Reno for a weekend he can't afford. The middle-aged husband recovering for six weeks after bypass surgery. The retarded 38-year-old daughter of frail aged parents, doing OK at a sheltered workshop but with no group home in sight. The 43-year-old man dying at home with AIDS.

What Do They Need?

LAMENTABLY FOR A HEALTH CARE SYSTEM that needs to buy and sell, most chronic care needs are not for discrete billable procedures but for homey help that *maintains* rather than *cures*. In order to understand the special care needs of the chronically ill, we need to acknowledge the care needs of the healthy. If a healthy child grows to be a healthy adult and dies without any time spent chronically ill, that citizen has received a lifetime of care from mother, friends, spouse, which we could call a , the lifetime total in hours (or dollars' worth) of unpaid care. A chronically ill person needs more than a ; that person receives a total lifetime of care we could call $a + x$, x being the lifetime total of special care for the chronically ill.

Let's call a the Basic Tending Minimum. What is the Basic Tending Minimum in the U.S.? In my household of origin, it included the table set with placemats and silverware at breakfast and something different to eat every morning. In my household now, the knives, forks, and spoons are in a cup in the middle of the table. Breakfast over the nine-minute period between being dressed and the commute is half a grapefruit at the table and toast in the car. In my idolized best friend's house back in high school, no meal was ever eaten *en masse*, and breakfast was a

sophisticated doughnut at school. Is there a study of the Basic Tending patterns of U.S. residents? We could measure the change over our lifetimes. In line with my three-day-old baby at the fish restaurant, the ladies ahead of us first cooed, then gained courage and scolded me for bringing her out in public. "I didn't take my children out of the house 'til they were eight weeks old," said one. These are trivial examples of a very important point. The Basic Tending Minimum starts with infant and child care. Family-leave legislation and the child care arrangements of professional men and women in line for federal office cast new light on an old issue. If everybody should be at work, yet we still believe children require care based on the model of at-home moms, each in their own home, who's at home? And what's a reasonable price to pay to duplicate that beloved model? Low- and middle-income families may pay 15 percent of their income for child care. Had an early U.S. attorney general candidate paid 15 percent of her \$507,000 income for child care, the child care salary in her household would have been \$76,050. The Basic Tending Minimum issue has many political, economic, and social ramifications, including the value placed on it through wages.

But we're talking about care beyond the Basic Tending Minimum for the healthy, about extra care for the chronically ill and disabled. Those unlucky enough not to have a pal who's a home-care nurse have no idea of what happens in the home these days—babies on ventilators, people with IVs, everybody on oxygen, sleep monitors for babies at risk for Sudden Death. Family member caregivers may be responsible for a complicated agenda—a nursing care plan, in fact—which may include medication, exercise, diet, and other treatments.

Lamentably for a health care system that needs to buy and sell, most chronic care needs are not for discrete billable procedures but for homey help that *maintains* rather than *cures*.

The technical and medical interventions taking place at home can be enormously helpful and are certainly attention grabbers, but they deflect the public gaze from the central task of caregiving—being there, watching and waiting, supervising, monitoring—being there and not being able to leave because those being watched can't do it on

their own. Do what? In nursing, health services, and geriatric circles, we talk about the Activities of Daily Living, those things you have to be able to do to get along—bathe, groom, dress, eat, use the toilet, move. Frailty gets defined by the absence of any of these abilities, and they are a severe measure indeed. If you can't do them, you are in dire straits until someone comes to help. We also have

Instrumental Activities of Daily Living—like using the phone and handling money. Being unable to do them means another level of dependence.

Consider the first half hour of my shift as a home health aide for Miss B, an 82-year-old woman living by herself in the home she grew up in.

I let myself in through the kitchen door at 8 A.M.

"Miss B, I'm here." I can't understand what she says from the bedroom, but she's not yelling, so I go to the kitchen to start water for tea. Fill the pot, put it on the stove, the light sputters. Is the propane running out? Remember to call the propane man. Enter the bedroom.

"How did you sleep?"

"Poorly, poorly." Sit her up in bed. The sheets are wet; they will have to be washed. It's raining today; is there room to hang them in the cellar to dry? Find a dry shirt, pull off the wet gown, quickly look at the sore on her back before she gets cold, put on the dry shirt. Swing her out of bed, let her feet dangle, don't get her up too fast. "What about breakfast?"

"Do I have any oatmeal?" Put her in slippers, robe. Walk with her to the kitchen. Seat her at the table. Open the oven door and turn it on to heat up the kitchen. Boiling water over the tea bag, get out a cup and the sugar and a spoon. Pour her a cup of tea and put it on the table. No napkins left, use a paper towel. Start the oatmeal. Start a grocery list for her niece. Find the radio station she likes. Smell the milk—is it sour? Yes, it is. Is there any dry milk? No.

"How about condensed milk on your oatmeal?"

"Yes, that'll be good." Stir the oatmeal, turn off the heat.

"Can you find me the mail from yesterday? It's on the davenport in the front room. Bring me the blue envelope . . . Can you read this to me? It looked important, but I couldn't figure it out."

It's an ad for a Medigap insurance policy; because the bold type on the envelope said "You May Not Be Covered . . ." she feared she was losing her Medicare insurance. Serve the oatmeal, more tea.

"Are you OK there while I go change the bed?"

"Why do you have to change the bed?"

"Well, the sheets are wet."

"How'd they get wet?"

"Well, I think you may have peed on them in the night?"

"Oh no, don't tell Donna [her niece]."

"I have to tell the nurse."

"No, please don't." (She fears she has another bladder infection, which means a trip to the hospital.)

"Well, just let me go start the laundry."

"Oh, sit with me while I eat, then go."

How Does Chronic Illness Care Get Done?

HAD I BEEN THE NURSE writing the chart note opening Miss B's case, I would have recorded Miss B's own words, "I want to stay in my home and Donna says I can't be there alone." What were the

structural supports available to address Miss B's problem? She had no pension but did get a small Social Security check, which covered her meager living expenses. She had Medicare, the federal illness insurance program for acute hospital and physician care available to persons over 65. She paid the premiums on a Medigap policy, a private insurance policy to cover categories of expense not included in Medicare. In those highly unregulated days, the utility of that policy was even more questionable than it is now. Then, as now, Miss B and all elders paid more out of pocket for health care than they did pre-Medicare.

Living as we do in a land where health care is distributed by ability to pay rather than by a simple mechanism of, say, standing on U.S. soil, we are habituated into believing that the way we take care of chronically dependent people is *the* way, or a natural way, or even a good way. We should remember that the rest of the industrialized world does not care for the chronically ill in the way we do. Home visitors, home care allowances, community rehabilitation centers, meal service, home remodeling to suit disability—these and many other mechanisms are the rule rather than the exception in the rest of the industrialized world. In the U.S., long-term care is done first and foremost by unpaid family members and friends, with unpredictable and irregular community supports, and only secondarily by institutionally based care—care by paid workers either in the home or in institutions. The patchwork of long-term care in the U.S. means that you may or may not be in the insurance category that pays for certain types of long-term care. Then you may or may not be in the right geographic area to get the care you need—for example, diagnostic and management services for your child with autism. And the institution or the services that you might be eligible to have paid for and that might be open to you may not be good enough, or what you want. Cost, access, and quality—these are the trinity of health care, the titles of the problems *and* the solutions.

Had Miss B sought institutional care, she would have faced those three problems—no bed, no way to



The Patient. Dry point by Celia Calderón de la Barca, 1950.

pay for it, and little say in her care. She would have been on a long waiting list for a nursing home bed and in fact would probably have found no bed within a 50-mile radius of her rural home. Had she found a place, her small income and slightly larger savings would quickly have been exhausted by the costs of nursing home care, and she would have, in the parlance, “spent down” to a level of impoverishment that would have qualified her for Medicaid (not Medicare) payments for nursing home care, had the institution been willing to turn a “private-pay” bed into a “Medicaid” bed. (Since Miss B’s day, some states have instituted significant Medicaid reforms, including the ability to hold onto some assets. Careful—some would say unscrupulous—estate planning has also enabled higher-income families to qualify their elders for Medicaid.) A third aspect of the institutional care then available in that corner of the rural northeast would have troubled Miss B deeply, as a lifelong New Englander whose local government included the yearly town meeting: nursing homes may be socially unhealthy and are certainly undemocratic, with little patient autonomy and even rarer patient-led governance. Miss B might have also been profoundly affected by the quality of the health care in an institution; would she have been sicker or healthier there?

Was there no middle ground between unsafe at home alone and a nursing home for Miss B? Yes, there was. It was the care organized by Donna, Miss B’s niece, of which I was a small, paid part. Miss B needed assistance with ADLs, which I supplied on the weekdays. On weekends, Donna and the great-nieces cooked breakfast, cleaned, and brought Miss B over to their home for dinner. Miss B needed assistance with IADLs—money, telephoning, getting to the voting booth. Donna handled the money; when I was in Miss B’s home I did her telephoning, and I once took her to vote. Miss B needed goods (food, clothes) and services (doctor visits, church), companionship, and occupation. For an eighth of every weekday, I was in Miss B’s home, meeting some of those needs. I was employed by a private, not-for-profit homemaker agency that received a

budget allotment from the town in which Miss B lived, making her eligible for home aide services at a rate slightly less than she would have paid on her own. The visiting nurse also came every two weeks, subsidized by the town’s payment to the regional visiting-nurse agency as well as by state and federal public health money for noncategorical care (no longer seen post-Reagan).

But the responsibility and most of the work of caring for Miss B fell to Donna, including the initial decision that Miss B couldn’t be home all alone. It was Donna’s work to pay the bills, to be her building superintendent, to take her to the doctor, take her to shop for clothes, include her in family gatherings, take her to church. Studies of caregiving find that caregivers who do not share the home with the frail elder may add the equivalent of a part-time job—20 hours a week or more—in care work. (Caregivers who share the home tend to do even more, though figuring out what work is for whom complicates the calculation.) Donna added her work for Miss B to her schedule of full-time paid employment and the caregiving work for her husband and several small children.

In many ways, Donna typifies at-home caregivers. First and foremost, she is a woman. Women are the overwhelming majority of unpaid caregivers of the chronically ill. Like most caregivers, Donna has other paid and unpaid responsibilities. She is willing to take on the responsibility for her aunt and expresses some satisfaction from doing so. But like all caregivers, Donna is worried by a future for which she is unable to plan.

Who else besides people like Donna take care? The middle-aged bypass patient has his wife stay home from work to care for him in the first two weeks of his postsurgical recovery, and then a son comes home from college for the following week. My friend sends a monthly check to her chronically schizophrenic brother in care of the liquor store owner in the neighborhood where we all grew up. The liquor store owner is a high school classmate of her brother’s and acts as his bank. The man with the motorcycle injuries—no one wants to take care of

him and his job losses and impulsive trip to Reno, not his wife, his lover, his mother, or his boss.

Since Miss B's day, we have seen the stuttering development of long-term-care insurance, the growth of privately funded retirement communities for urban-dwelling persons richer than Miss B, and the growth of publicly administered, complex categories of home care. Funding for public health nurses and aides has decreased. Though many structural changes in long-term care have taken place, they are tinkering at the margins while the central question lies not only unanswered but largely unasked: *Who will take care?* As important as the structures for care is the social context for Miss B's care, which is based on the expectation that women will take care. Or men without the choice

not to care. The upshot is that chronic care in the U.S. long-term-care vacuum gets done by those with little or no choice: unpaid women at home and low-paid women, especially women of color, in institutions. These women provide care because of habitual gender bias we mistakenly believe represents the natural order of things.

What Are the Consequences of the Status Quo?

THE DEMOGRAPHICS OF AGING, the increase in chronic conditions among all age groups, and the long-term-care vacuum in the United States mandate care at home for those who cannot afford or use institutionally based alternatives. Most of that care is provided by women, who must add unpaid labor to the rest of their paid and unpaid responsibilities.

**The technical and medical
interventions taking place
at home deflect the public gaze
from the central task
of caregiving—being there,
and not being able
to leave because those
being watched can't make it
on their own.**

While I do not intend to ignore the benefits of home care, I nonetheless suggest that we may be using flawed data—for example, patients' and families' expressed reluctance to use institutionally based care—to mask larger forces, political expressions of gender and class bias such as the belief that institu-

tional care costs while kin care is free, public reluctance to spend money on work regarded as inconsequential and thought naturally to belong to women, and a tendency to ignore the discriminatory burden placed on women and lower-income families by the absence of a predictable long-term-care system.

The language of long-term care disguises the extent of the work and obscures those who do it. In my doctoral work on elder care, I encountered a limited litera-

ture and one hampered still further by revealingly biased language. Care provided to family members and friends was misnamed in at least three ways. It was called informal care, implying that it was unplanned, casual, and haphazard. Observers report, however, that there is nothing casual about care at home. Gerontologist Elaine Brody, for one, has written compellingly about women in the middle, at work outside the home with both children and aged family members to care for in the home (Brody 1981; Brody and Schoonover 1986). Members of the *sandwich generation* (Brody's term) have demonstrated the highest levels of planning and organization in carrying out their multiple caregiving roles. Care at home has been called free, as if no costs were borne by the unpaid worker. But there are costs which can be detailed and calculated (Ward 1987, 1990). And finally, care at home by family and friends has been called family care, implying that all members of the family participate equally.

But they do not. Women are the overwhelming majority of caregivers, and even when caregiving work is shared with males, women do more for longer. *Family* is code for *women* when we're talking about caring work.

I made up for what I decided were deficiencies in the language by making a lateral library move from nursing and social work to anthropology, specifically to the work of Micaela di Leonardo, who used the term *kin work* to describe the maintenance of a family network (di Leonardo 1984, 1987). I built on di Leonardo's idea and settled on the term *kin care*, defining it as all activities undertaken by family members or friends that supplement or replace a person's abilities to perform the tasks necessary for independent living. Gender is still obscured by this term, but I couldn't figure out a way to say Work Done Mostly by Women Most of the Time.

How central are gender considerations in kin care? Consider this story.

C was ecstatic about the promotion. Going home with the news, telling the family, and daydreaming about the fattened paycheck were great moments. But sleep proved impossible that night as C realized that the travel and extended hours the promotion would entail were not going to mesh with the growing needs of C's father, Joe. Joe's memory lapses and recent broken elbow resulting from a fall made C's daily visits no longer a nicety but a necessity. Shopping with Joe, taking him to the clinic, and balancing his checkbook had been C's responsibility for years. But in the last six months, C also took on arranging Meals on Wheels for Joe, taking his clothes, sheets, and towels to the laundromat, cleaning his apartment, giving him a tub bath once a week, and bringing him over to see the kids each weekend. As C said to the supervisor, "I really want the new job, but I have to consider my family responsibilities first. I can't take care of my father and do the new job, too. So I'm afraid I'll have to decline the promotion and stay at this level a few years longer." The supervisor was irritated. "Too bad, C," he said. "A smart

person like you could go far in our firm. An opportunity like this may not come again."

On first reading, do we assume C is a man or a woman? Does it make a difference? Would the reactions to C's dilemma as well as the responsibilities C has accepted differ, according to C's gender? If C were a man, would his decision to defer promotion be more costly, and would the care he provides his father represent a greater sacrifice?

What are the consequences of the long-term-care status quo in which women are obligated to labor? I'll consider three areas—ethics, economics, and politics—pretending they are separate.

Ethics

WHAT DOES IT MEAN for the nation's ethical health that giving care—tending, nurturing—is the work of women? Feminist scholar Dorothy Dinnerstein has told us that because rearing children is the province of women, our society is doomed to denigrate women. Dinnerstein says, "People under the most diverse cultural conditions seem to feel an opposition, an antagonism, between what is humanly noble, durable, strenuous, and the insistent rule of the flesh, flesh which is going to die and which even when death is remote makes humbling demands: we must feed it, we must let it sleep, we must get rid of its smelly wastes" (1976:126). Does this underlie our distaste for the homey duties of caregiving and our assignment of them to those who can be made to feel obligated to care?

Society may denigrate women for their flesh-bound concerns at the same time that it persists in reinforcing them. Those women who resist the societal pressure to provide kin care are accused of gender betrayal. They may be accused even when they obey that pressure. The myth persists that children do not care for their elders when the evidence is overwhelming that they do.

Some women may internalize society's pressure so deeply as to resist help. It is a common story among nurses trying to convince weary wives and daughters to get some relief from caregiving that those wives and daughters cannot allow an alternative, even when it's shown to work well. "He doesn't like strangers in the home." "I don't think I could let someone else take care of him." Do caregivers have any role in making sure the work falls to them?

Studies have shown the reluctance of women to accept respite, and intervention programs have been implemented to make respite acceptable—to persons of various ethnic backgrounds, for example. But how can it become acceptable to ask for help, when it is clearly *unacceptable* to say "I don't want to care for my father" or even "I'll do part, but you have to do the rest."

The same societal pressure surfaces with regard to public acceptance of couples who don't want to have children, for example, or over the benefits of out-of-home child care. We expect women to want to take care and thereby deny them the exercise of choice.

A children's book, *The Giving Tree*, by Shel Silverstein (1964), provides a chilling picture of the idealized giver. A tree loved a little boy. The boy used her leaves to build crowns, but as he grew older, he grew tired of playing under the tree and needed more than leaves, specifically money. The tree said, take my apples and sell them. And the boy did. Later the boy came back as a man. He didn't need money, but he needed wood to build a house, so the tree said, take my branches. And the man did. As an old man, he returned and asked the tree for a boat in which to sail away. The tree said cut me down and make a boat. And in the very end, the tree—now a stump—*apologized* to the very old man when he returned,

needing help again, for having no more apples, branches, or trunk, but offered the old man her stump on which to sit and rest. In each act of giving, "the tree was happy." As Mary Daly points out, in her stimulating book *Gyn/Ecology*, this tale is "primary programming for gynocide. [The tree's] degradation is total, for the giving tree wallows in self-destruction. Here is a model of masochism for female readers of all ages, and of sadism for boys of all ages" (1978:90).

Readers might recognize this book for the twisted model of giving it presents and yet still underestimate the power of the public assumption that women will take care. What arguments could be powerful enough to dissuade us from our belief that women are the ideal caregiving center of the nuclear household? Can data do it? We visit and revisit the data that indicate the benefits of good out-of-home day care to a public still resis-

tant to changing the model of mom at home. I would predict that a great deal of such resistance would have to be overcome before unbiased evaluations could be made, for example, of day care for sick children. Even if we could demonstrate that children do better in day care than at home when they are mildly ill, that they recover faster, have fewer complications, and receive better health care supervision, a powerful social element preventing the growth of such day care would be the feeling that sick children ought to be at home, tended by mom. I may have those feelings myself, but I want to point out that these are not immutable rules but culturally and socially molded constructions.

Women who provide care can find strength in religion, even as religious traditions may enforce their acquiescence to the role of caregiver. For some of them, religious fatalism is a default response to a

Care at home by family and friends has been called family care, implying that all members of the family participate equally. But they do not. *Family* is code for *women* when we're talking about caring work.

nonsystem of home care that affords them no choices. For others, it exalts an obligation whose fulfillment is a source of pride and pleasure. Many women in our study of low-income women caregivers (Ward and Carney 1992) constructed their own rationale for taking on the care of disabled family members. One respondent introduced the religious or spiritual reference point used by many women. "Well, sometime I get really disgusted and I pray a lot, you know, because, uh, sometime I be so lonely because I cannot get to church and I cannot, you know, maybe take a walk or something like that. Sometime it gets so lonely, really lonely."

Another respondent acknowledged that she had demonstrated strength by caring for her totally disabled husband, but she credited her religion with enabling her to know her own strength. "And I would advise anybody, 'Let go. Don't hang with it as long as I did.' By me being a Christian I know I am strong, that's the onliest way I survived."

For the abused women in this small sample, acquiescence to caregiving included dramatic elements of ambivalence. They acknowledged the irony of having control and responsibility for a partner under whose threats and abuse they had lived. This respondent credited her religion for diminishing and controlling her hatred:

Respondent: Well, before all of his Alltimer's [Alzheimer's], he was a tough man. He was . . . I'm what you call . . . what you call these wives?

Interviewer: A battered wife?

Respondent: I was a battered wife before he had Alltimer's. So they say they gets meaner. I told my girlfriend, "He can't get no more meaner." As he is, can't do nothing but sit here and . . . and I have to, you know, be the one to help him. It comes to my mind, now I remember the time when you took me for a bat-ball. And so now I sit down, but I have prayed, and the Lord have removed that hatred out.

Interviewer: Is it your prayer that made the hatred go away?

Respondent: Yes, 'cause I really had it, I felt like doing it him what he did to me.

Such religious motivations may also play a part in prompting other family members to assist the caregiver. One woman described the assistance she got from even her youngest grandchild. The severely demented care recipient moaned and cursed all day, and his caregiver had found that rubbing his skin with lotion soothed him:

I'd rub him, all the kids would rub him, all the kids was in the room with him. I got [grandkids]—I got a ten-year-old, eleven-year-old, and five-year-old. And that five-year-old could handle him better than I. She could calm him down. She would say, "Papa," if he cursed, "Papa, pray" (and fold his hands). "Our Father . . ." And she'd pray with him. Then she'd say, "Now papa, go to sleep." Cover him up to here, just rub him, she say, "I'll be right back." And she'd hear him hollering again, run get a piece of bread. They thought giving him bread would stop him. And all three of the little birds would take turn, breaking up his bread, putting it in the mouth. "Now, papa, eat that and you don't have to holler." He would just eat it and he'd sleep. And they would get up in the bed and they all would rub him. Just keep rub him. And when he wake up, they would say, "Papa, how you feel?" and sometime, he'll say, "All right." (Ward and Carney 1992)

Thus we have the socially constructed model that places caregiving in the center of women's concerns. Can we imagine studies that would convince the dubious that placing caregiving first is bad for women? A mixed portfolio of activities has been shown to be healthy. For instance, in a study of widows, paid work history and attitude toward work were shown to be significant predictors of health during bereavement (Aber 1992). Despite evidence that supports a range of choices about caregiving, the assumption that women will provide care (and that they need not exercise choice) is the bedrock of chronic care.



Grandfather's Little Nurse. Oil on canvas by James Hayllar, ca. 1880.

Collection of Galerie George, London. Photo: Bridgeman/Art Resource, New York.

Economics

ANDERSON (1990) HAS EXAMINED the economic ideologies underlying a number of movements away from institutional care, movements such as deinstitutionalization, normalization, and independent living for those who are disabled or mentally ill. Anderson writes, "The deinstitutionalization, normalization, self-care, and independent living movements should . . . be understood in the context of the need to control institutional expenditures and do not solely reflect the emerging knowledge of health care professionals and the desire to promote the independence of the client" (1990:72). Low-income caregivers bear the brunt of the enthusiasm to keep care at home. Anderson wonders, "Society as a whole has not made adequate provisions to assist people in the management of their care, and so researchers must ask why this has not been done" (1990:77). High-technology care renders profit, she states; low-technology care does not. In fact, low-technology care costs institutions in labor intensity, so turning it over to the family saves money for institutions.

Government politics and policy share this motivation to save money through reliance on kin care: the political reluctance to address long-term care arises out of the belief that the costs will be prohibitive. As long as kin care is believed to exact no public cost, it is a preferable alternative to the commitment of public funds. As long as kin care is free, it's the best.

But consigning women to unpaid caregiving creates an economic ghetto built on women's disproportionate sacrifice in earning power. A new study quoted in the *Wall Street Journal* (10 February 1993) reports that women who temporarily leave the work force experience an average 33 percent drop in wages when they return, and their pay never catches up with that of women who continue working. Other costs paid by women who take on caregiving have not been added up; they could include losses in opportunities for job promotion and losses in pen-

sion benefits. Something is known of the cost in health, which suffers in women with heavy caregiving responsibilities, and in well-being, which decreases as the demands of kin care rise. If we consign women to kin care, do we not create another generation of poor and potentially unwell women who in turn will be forced to call upon their female kin for unpaid care?

Women providing kin care make valiant, individual efforts to combine paid and unpaid work. Institutional supports are available in some businesses, through flexible work hours and leave policies. But troubling issues underlie these gender-based efforts, such as "the mommy track," a proposal to divide the work force into fast-track workers who lack (or can arrange to appear to lack) family responsibilities, and slow-track workers who have (and can't pretend not to have) family responsibilities. The question continues to be debated: Is it reasonable or fair to divide the work force in this way?

Those women who would follow the social mandate to provide kin care find little publicly supported assistance; they have to do it alone. Those who resist the mandate and look for institutionally based long-term care find barriers, a central one of which is that only those who can afford to are able to use alternatives to kin care. This is the quandary of health and welfare services in a capitalist system.

Politics

WHEN ELAINE BRODY TESTIFIED before the U.S. Senate about the strain women experience when working outside the home while also caring for their aged relatives, a senator asked: Why don't women just stay home where they belong and not be strained? He reflected a widespread belief that a significant amount of family work is naturally the work of women. Stephanie Coontz, in her celebrated book, *The Way We Never Were*, discounts the myth of the nuclear American family tended by mom. Coontz won't buy generalized appeals to the good

old days of the American family; she wants to know which good old days are being referred to. Colonial days, when death meant that average years in marriage were less than a dozen? The Victorian era, when the proportion of servants to white households was one to nine? It was probably the sentimentalized and idiosyncratic 1950s family that formed the senator's dream. Relevant current facts include the number of total years devoted to child rearing in modern families, which has declined; modern families have fewer children and more years pre- and post-child rearing. But the number of years devoted to elder care has increased. Care of the elderly was never a major function of families in the past, but it has become so today. Promulgating the myth that Americans are failing in their duty toward their family elderly seems a convenient social pressure mechanism to avoid centralized responsibility for the elderly, promoted in a society with a political culture of individualism, and a healthy dose of sexism thrown in. Coontz argues that blaming the family is a tried and true but ultimately fallacious response to social crisis.

Suppose we followed Coontz's call to stop relying on women to make myth reality and instead developed community-wide responses to the long-term-care crisis. Could we turn our entire long-term-care system on its head and make institutionally based care (which can still take place in the home) the standard, and unpaid family support the additive? Patients' preference for care at home is an important consideration and is used as a rationale for perpetuating unpaid kin care. But I believe our measures of preference are deeply biased. It is a standard of research methodology that we make comparisons. It's not enough to say, I choose this, but instead we should say, I choose this instead of that. So when patients are asked about their preferences for care, we must attend to the range of

options they choose from. If presented with the choice between a known commodity, home, and the commonly held picture of institutional care, which would you choose? Suppose instead that the alternative to home care is a superior adult day center, with age-appropriate activities and field trips, regular visits by the podiatrist, excellent meals eaten with others.

How foreign are such daydreams? How embedded are our current patterns of distributing social welfare? Feminist geographers urge us to look to the organization of our physical space to understand how deeply our habits of discrimination are ingrained. Leslie Kane Weisman writes in *Discrimination by Design* (1992) of the mismatch between diverse types of households and housing uniformly designed for

The political reluctance to address long-term care arises out of the belief that the costs will be prohibitive. As long as kin care is free, it's the best.

nuclear families—a mismatch she contends has consequences like homelessness, women battering, and unhealthy child-rearing practices. Apply her argument to long-term care and imagine a community designed to include the chronically ill. All kinds of interior design changes could help—safe bathrooms with grab bars, closets with movable racks accessible to those in wheelchairs. But think larger—schools as public service centers with the neighborhood health clinic and day care for the frail elderly as part. The whole neighborhood comes to school for lunch—the elders, the preschool kids in day care, the college kids home on break, the neighborhood factory and office workers. Even the visiting phone repairman, in the neighborhood that day repairing phone lines, would know he could use his lunch card to come into the local school to eat with the folks. You see that your mom is getting frailer, so you get on the list for one of the apartments linked to the community health worker's office. The legal and financial arrangements stand ready-made to set up housing partnerships; my friends and I, with our

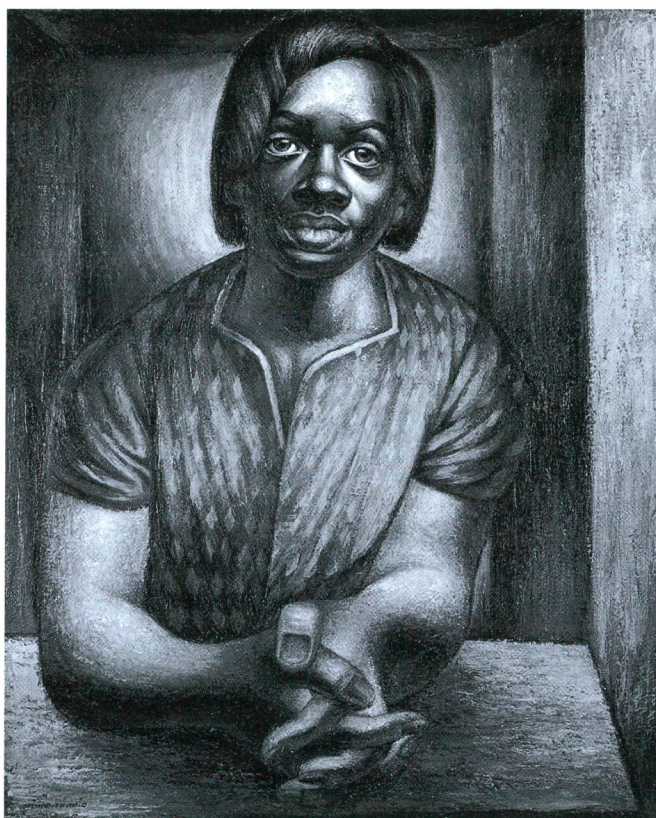
kids grown, decide to combine households. We sell one house, split the proceeds, and move together into the other. College housing is built with reduced rates for college students willing to share housing with elders who need help with shopping and heavy chores. Land zoning, as Weisman points out, would be reformed, and single-family exclusionary zoning would be eliminated. And instead of single-family homemakers, each in her own box, community ser-

vices for cleaning and meal preparation, and the enjoyment of shared spaces.

These ideas threaten many assumptions about chronic care in our communities, and none more central than the idea that women—and some men—will do the caregiving work, and that they need not be offered a choice. Is this fair? Is it just? And can we risk asking? ☸

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Woman Worker. Oil on canvas by Charles White, 1951.

Collection of Walter O. Evans. Courtesy of the Heritage Gallery, Los Angeles.

Response

An Alternative for Miss B

Gloria I. Miller

I HOPE THAT I WILL LIVE LONG ENOUGH to see the day when I can drop by a nearby school to join others from the neighborhood for lunch and to find Miss B joining us instead of remaining isolated in her own home. Debbie Ward's envisioned community where the needs of the elderly are met by all, and for the benefit of all, presupposes some radical shifts in attitudes and responsibilities. These shifts are needed if the U.S. is ever to implement a plan that meets not just the health needs of ill individuals but those of the entire community.

How we get there from here will depend on a number of shifts: from a reimbursement-driven model to one that responds to need, from the care of illness to the care of health, from an expectation that chronic needs will be met privately to a recognition of the public obligation to meet the needs of all. These shifts will help to lift up the work that is now being done mostly by women to its rightful place as an essential element of health care. Underlying these shifts there must be a sense of community—one that

extends help to those in need and also provides an atmosphere where help can be accepted and welcomed.

These shifts should improve the status of women, because much of the slack in the current system is being taken up not only by women who provide "kin care," but by those who are hired to provide care for the elderly and disabled for minimum wages and poor benefits, for example, minimal or no health insurance. They frequently bear a great deal of responsibility for the day-to-day care of their charges with little or no training or supervision. I will focus here on these paid workers, who play an unrecognized yet significant role in health care, especially for the elderly. Miss B, for example, would not have been able to remain in her own home if Donna had not hired help to see that she was fed, clean, and safe.

The present confusion of job titles (home health aide, attendant, chore worker, homemaker) varies more according to funding sources than to clear differences in roles (Fine 1986:13). I use the more generic term, *home health worker*, to include all those who are hired to care for people in their homes. These workers are quickly becoming the backbone of the health care system even though they officially

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remain outside its structures. Almost half are foreign born; almost all are poor women with little education and little potential job mobility. Despite such limitations, they are called on to bear a great deal of responsibility for people with varying degrees of illness and disability and to provide them with emotional support as well as physical care. They do essential work without adequate backup support for themselves and with poor remuneration (Chichin 1988:98–99). Currently there is little third-party reimbursement for provision of what Ward calls “homey” tasks. Medicaid provides some assistance to the poor who meet eligibility criteria, but these benefits vary widely from state to state. In California, providers of this care are paid minimum wage, and the quality of services varies greatly. Many of these women work without nursing supervision, restrictions as to which tasks they can perform safely, limits on the length of shifts, and, in some cases, fringe benefits. Financial constraints on both caregivers and those in need of care often lead to these more informal employment arrangements, which can do a disservice to both parties.

The current system of reimbursement makes clear demarcations between acute illness and chronic conditions. Financial incentives still lie in tertiary rather than in primary care despite some preliminary efforts to change this pattern. Under this system, the work of providing for the activities of daily living, which can be a very complex and time-consuming process when capacity is diminished, falls on people like Donna, who either directly provide the care (often at great personal or financial sacrifice) or see that someone is hired. Yet, left without “homey” help, Miss B could fall, forget to eat, or lie for days in her wet bed without being found, and any one of these factors could lead to acute problems.

If health care were viewed as a continuum spanning the full range of activities that restore health or manage chronic conditions rather than as strictly medical procedures and skills, the care that Miss B needs to stay as healthy as possible would be provided, and Debbie Ward’s role in her care would be considered an essential part of the system rather

than a means of fulfilling Donna’s responsibilities.

The dualism prevalent in Western thinking has placed the mind above the body and has relegated the care of the body to the private sphere. Ethnologist of nursing Patricia Benner defines two paradigms for understanding personhood in Western industrialized societies: the control paradigm (associated with masculinity, objectivity, and mechanism) and the caring paradigm (associated with femininity, caring, and connection) (1990:6). This dualism is manifested in the way the health care system classifies needs into the social realm and the medical realm. An example of this is the separation between “skilled” and “unskilled” care. The job of home health workers is considered unskilled, therefore fulfilling social rather than medical needs, although proper nutrition, exercise, and hygiene directly affect health (Fine 1986:15). But because health care is considered to be in the technical realm, the home health worker is not part of that system.

Some integrated programs being developed provide hope that the system can change and be more responsive to the needs of all without requiring any one group to bear the burden of cost or labor. In the northeastern sector of San Francisco, On Lok Senior Health Services has been in operation since 1971 and serves as an example of how shifts in the health care system can lead to better care that is also cost effective. The present program, which currently serves over 350 participants, evolved from a study whose original purpose was to determine the need for a nursing home in the Chinatown district. What began as a demonstration project is now a well-established program, capitated under Medicare and Medicaid, which has been replicated in eight sites in the U.S. On Lok’s program, patterned after the English day hospital, targets the very frail elderly certified to need either intermediate or skilled nursing care.

A multidisciplinary team provides the full range of medical, nursing, social, rehabilitation, personal care, and transportation services at On Lok’s four day-health centers. The day-health center is the mainstay of the program. All participants who are

able are transported to a center at least one day per week. There they are closely monitored by a physician or nurse practitioner, and they receive a full range of services that may include nursing care, physical, occupational, and speech therapies, and a variety of social activities. Chronic conditions are managed so that acute complications are minimized. The home health staff attend those who are unable to come to the centers. Social workers determine whether participants and their families need additional services or assistance with housing arrangements.

Most participants live alone either in their own homes (34 percent) or in On Lok supportive housing (32 percent), while 27 percent live with others in the community and 5 percent in inpatient facilities. In addition to day-health services, On Lok also provides in-home support services, transportation, and meal delivery to participants in the community. One of the day-health centers shares a building with a children's day-care center, which permits children and elders to mingle. Nearby facilities provide inpatient acute and skilled nursing services on a contract basis, but all care for participants, regardless of site, is coordinated by the multidisciplinary team, which plans and regularly reviews care for all participants. A consistent effort is made to support participants' ability to stay in the community, which is reflected in the low percentage of inpatient days (Eng 1987; Kane 1992).

Because On Lok's funding is based on a capitated system, restrictions on using funds for "skilled" or "unskilled" care do not apply. Decisions are made on the basis of need, and services that would not be reimbursable under the standard Medicare program

can be provided. Although this model has been shown to work well in its locale—an ethnically diverse (predominantly Chinese and Italian), densely populated, small geographic area—creative modifications might be required in other settings.

If Miss B were enrolled in such a program, a home health worker employed and supervised by On Lok would come in the morning to get her up, give her breakfast, and get her ready to be picked up and taken to the day-health center. There she could be evaluated and treated for her possible urinary tract infection without the need for hospitalization. She could have a shower, eat a hot midday meal, and participate in a variety of social activities. Donna would be relieved of worry that Miss B might be hurt or be in need of help when she spent much of the day alone.

Much as Debbie Ward's closing lunchroom scene seems to come out of a culture far removed from that of the mainstream U.S., programs like On Lok's demonstrate that a movement in that direction is feasible. The provision of "homey" solutions along with professional care for both chronic and acute needs can be a cost-effective alternative that is also qualitatively more acceptable than institutionalization. Individuals in need of care can remain in the community, and the women who have traditionally been the providers of "kin care" will be relieved of some of their burden by supervised staff trained to care for the elderly. The picture will be complete when those who prepare the lunch at school and clean up after it are women and men who are paid a living wage and have full access themselves to the health care system. ☉

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Caring. Charcoal on paper, 1988. From the series *Bearing Witness*, by Boston artist Michael David.

Reproduced courtesy of the artist.

Response

Not Gender but Economics

Raymond J. Lawrence, Jr.

DEBBIE WARD RAISES AN IMPORTANT and troublesome issue for reflection, but her conclusions are ultimately unacceptable. The central and very perplexing question she raises is, What drives this society of ours to hold so cheaply the work of caring for its weaker members, the aged, the young, and the chronically ill?

To give Ward the credit she deserves, the principal vision that inspires her is compelling and Augustinian at its roots. She seeks an all-embracing community in which private self-interest is attenuated for the sake of the less powerful, the elderly, the young, and the chronically ill. As she points out, even such things as our zoning restrictions brutalize the old and sick. We protect our property values with our single-family exclusionary zoning that makes it impossible for many of the elderly to remain in their homes by taking in boarders or by creating group homes. Ward's vision of a lunch served for all at the local school is a fragment of her

Augustinian vision in which the whole community, including the weakest members, convenes itself for the purpose of satisfying the needs of all, especially the most marginalized. In Augustinian terms, personal wealth does not belong to us in any exclusivist sense. It is entrusted to us for the benefit and pleasure of all the children of creation, us and them.

Ward is correct that our deeply entrenched rugged individualism is turning in on us. We prefer to believe that families should take care of their own, which is translated in the real world to mean that everyone is on his or her own. Rugged individualism militates against anything remotely akin to an Augustinian vision. The possession of personal wealth carries with it no social or communal obligation. Worse still, possession of wealth seems often to bring contempt for those who lack it.

How did we come to hold the care for our weaker members so cheaply? Ward's answer—that women do the work of caring for the weak and that the devaluing of this work is simply further devaluation of women by men—is not persuasive. She never explicitly states who it is that devalues women, but since in her construct women are victims, the alleged crime is placed squarely in the laps of men. In fact,

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women are as often as not victimized by other women, which leads to the obvious conclusion that something other than gender warfare is at work here.

As everyone (including Ward) knows, some men are actually doing the devalued work of caring for the aged, the chronically ill, and the young. The numbers are small compared with the numbers of women, but they are there, and their presence undermines Ward's case. She deals with this fact by asserting that males who do such work do so because they have no choice in the matter, a curious generalization. Furthermore, she adds that women caregivers are doing more and working longer than these men. She cites no data to support this gender-biased claim. Such reasoning reveals that Ward sees a complex and debilitating social problem only through the lens of gender warfare. Men who are now working as caregivers for the aged, ill, or young will be quite surprised to hear that they universally do less and work fewer hours than women.

Her insertion of a feminist agenda into the discussion merely obfuscates what begins as a promising exploration of a serious social problem. My guess is that the problem of why we hold so cheaply the work of caring for our weaker sisters and brothers is rooted in two sources: our economics, that is, our love of money and the power that money brings, and our deep and covert conflictedness about weakness in any form.

Elders (whether healthy or sick) are, like children, the first victims of our romance with free enterprise and our love of radical mercantilism. Men as well as women are targets of this neglect, and male children are as abused in our slums as female children. The alpha and omega of our social and political order is the measure of profit to investment. As long as our communal life is ordered by such a tilted vision, the young and the old, unless they possess capital, will go begging. Geriatric men as well as women suffer for lack of purchasing power. Ward does not discuss whether commonly agreed upon principles that govern the distribution of wealth are the root of the problem. She prefers the gender warfare theory.

Neither does Ward touch on the significance of the curious phenomenon in this country whereby women were suddenly driven out of the homemaker role by the sheer force of economics. Prior to about midcentury, one typical middle-class income sufficed to support a middle-class family with children. That is no longer true. Two incomes are now often required to support a middle-class family with children. A beneficial result of this shift has been the increased social liberation of women. But a negative effect has been further to raise the ante on the middle class, especially the lower middle class. Driving both parents into the work force provides a much larger work force, keeping wages lower, which in turn pushes lower still the wages of paid homemakers and caretakers who replace the working women. Whatever the other consequences of this change, it has strengthened the grip of those who are in possession of private wealth.

If a conspiracy to neglect the weak exists, and I believe it does, it is not a conspiracy of men against women but one of the economically powerful against the economically weak.

Our social order is deeply conflicted over weakness in any form. Heroically we rescue neonates in our high-tech medical centers, and when they are strong enough, we send them home to the slums to wither for lack of nurture. We dehumanize the dying process at every opportunity. Providing meager care for the young, old, and sick is just doing more of the same. We eagerly make multimillionaires out of people who excel in sports, demonstrating their strength and competitiveness, but with rare exceptions we expect the old, the ill, and the young to pay their own way or do without.

Ward makes reference to one of President Clinton's aborted appointments to the office of attorney general. His first two candidates were women whose nominations foundered on the questionable propriety of their hiring practices in employing nannies. Suddenly the issue of monetary compensation for child care was thrust into the public spotlight. Clinton's nominees were not middle-class wage earners. Had they been, their children would

have been sent to day-care centers staffed largely by minimum-wage earners, male and female. One of the nominees, with an annual personal income of \$507,000, sought, as is typical of upper-income persons, to hire a nanny who would work for minimum wage. Having difficulty finding applicants, she turned to undocumented foreign workers, a step that ultimately derailed her nomination. Had she been willing to lay aside 15 percent of her salary, the burden of the average female worker with dependent children, according to Ward, she would have been offering \$76,000 a year to a qualified nanny. Such a salary would have attracted graduate-level experts in child care in such numbers that she would have been unable to interview them all. It is intriguing that a woman earning half a million dollars a year would so insistently seek out someone willing to work for minimum wage to care for her child, even to the point of breaking the law. Something perverse seems built into our corporate way of viewing the work of caring for the young, the sick, and the aged. It is not the perversity of males wishing to abuse females: Ward might take note that in the case of Clinton's nominees women abused women. It is the strife of those who hold economic power against those who don't.

The United States is unique among industrialized nations in its neglect of its weaker members—infants, children, elders, and the sick. We demonstrate this quite clearly in the way we treat health care as a mercantile commodity, on a par with

If a conspiracy to neglect the weak exists, and I believe it does, it is not a conspiracy of men against women, but one of the economically powerful against the economically weak.

buying an automobile. Those who want it must pay for it. This nation has a phobia, a neurosis, about caring for the weak. Any mention of adapting the socialist safety nets of northern Europe to this country is generally met with horror. We provide all kinds of government safety nets for personal wealth—insured bank deposits, mortgage in-

surance, bankruptcy laws, subsidies and bailouts for important businesses. We are resolutely committed to protecting the right to unlimited personal wealth, but we retain a laissez-faire attitude toward the slums of our cities, which continue to function as the nurseries of an increasing percentage of our future citizens. The irrationality and self-destructiveness of such a stance is

obvious. No one can be optimistic about a nation with such a perverse ordering of values.

Ward hopes to address real problems of the old and the sick as well as the young, and she seems to have a clear if fragmentary sense of what is needed. Simultaneously, however, she wants to make war on men because of their alleged abuse of women. Her argument will give great comfort to bearers of wealth and privilege, particularly when they happen to be women.

Not gender but the enormous imbalance in the distribution of wealth is the root of the problem of our inadequate elder care as well as of our neglect of all those who are less than fully able to care for themselves. ☹



Limited. Woodcut by Milton Johnson.

Response

Who Will Care?

Frances Leonard

DEBBIE WARD'S THOUGHT-PROVOKING article takes on perhaps the most prickly ethical arena in the U.S. today: the provision of personal assistance to individuals who need it. The default of our social and health systems has thrown the task onto the shoulders of hundreds of thousands of people who are both unprepared for and highly resentful of it. Various circumstances—family expectations, low skills, or immigrant status—may constrain people to take on the task of caregiving. Those who provide personal services for pay often receive low compensation and few benefits and work under poor conditions. The family caregiver may feel bound to a role that is detrimental to her own health. Organized religions, which ignore the plight of paid caregivers, may actually compound the plight of family caregivers with praise and applause for their efforts and calls to self-sacrifice.

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The Role of Religion

SOME OF THE WOMEN INTERVIEWED BY WARD relieved their desperation through prayer, indicating that without such spiritual comfort, they could not have persevered. Questions of the role of religious belief in allowing an unbearable situation to be borne require attention. When a caregiver attests that without recourse to prayer she could not have kept on ("By me being a Christian I know I am strong, that's the onliest way I survived"), the issue of religion's role in continuing intolerable situations is disturbingly presented.

In counterpoint, do not people in desperate situations have the right to succor—from wherever they can find it? Are not Ward's respondents really saying that their beliefs eased their paths? Without knowing for certain, my guess is that they would be shocked to be confronted by any analysis that suggested that their spiritual beliefs were merely the Trojan horse for their oppression.

It seems to me that there is room for both analyses. Institutional religions have the duty to identify situations where piety is the handmaiden of abuse. This duty includes the careful education of

the flock to recognize unjust situations that feature their own exploitation *and to withdraw from them*, rather than to continue as participants. Such education, however, puts the burden on the victim to recognize political and cultural oppression while in the vortex of it, and at a time when she is overwhelmed with the exigencies of just taking care of mama. Religious institutions, therefore, cannot rest on their educational mission alone when social justice is at issue. The duty to see that markedly unjust cultural practices are resolved in the legislatures is incumbent on religious bodies.

Who would deny that recourse to the spiritual dimension demonstrably alleviates not considerable pain? And who would deny religious people access to that solace? The involuntary family caregiver, trapped by social expectations and the default of the American health care system, is entitled to whatever comfort she can find. The paid attendant, as well, although in some cases in an occupation freely chosen, more often continues in her low-paid, dead-end, insecure job only because she's an immigrant or a woman of color. She, no less than the family caregiver, is trapped. The fact that so many paid caregivers identify with a faith community and actively seek its support demonstrates the genuine relief afforded by religious faith.

Religion, then, can be either the instrument of oppression, prolonging the untenable, or an agent for good, fostering an attitude of genuine caring and providing recognition for some very difficult tasks that caregivers do well. It is the job of the faith community to be ever alert to religion's potential for facilitating exploitation and to insist on just social and medical services and laws. Only then will the caregiver's plea to the Almighty be untainted by her own exploitation.

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She, no less than the family
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The Disappearing Caregiver

ANY DEBATE ON CAREGIVING MUST FOCUS on paid personal service as the paradigm for the future, because of an inescapable demographic truth: the

family caregiver will not long be with us. She is a dying breed. Few people under age 60 today can expect to have a family member available to assist them in their final years. Eighty percent of unpaid family caregivers are women—generally wives, daughters, and daughters-in-law of the incapacitated individual. But the number of women who are available to give such care is fast declining on

the American scene. Note these trends and realities:

- Few women under age 40 plan to be lifetime homemakers—they won't be available to care for spouse or parent.
- The baby boom parented the baby bust. Families don't have four or five children—of which one might be free to help. Millions of couples in mid-life have no children or only one child.
- The increase in divorce means hundreds of thousands more single elders—with no caregiving spouse and possibly alienated children.
- Remarriages multiply the older relatives younger family members might respond to: stepparents, step-grandparents—plus the original parents. More older family members per child mean fewer available candidates to provide care.

All this means that efforts directed at solving the looming long-term-care crisis now that the baby boomers are approaching 50 should concentrate on paid personal services as the model for the future, not kin care. The de facto dumping of the duty on

the family that now passes as national policy simply cannot happen. Since the future of long-term care is in paid services, the aging community should be looking at solutions not dependent on family members' being ready and willing to help.

Joining Forces with the Disabled

TO SECURE THEIR OWN LONG-TERM INTERESTS, the aging population may do well to join forces with that other segment of the population in need of personal services—the disabled. In recent years, there's been a healthy, if not altogether harmonious, attempt by advocates for the aging and disabled to find common ground. Solidarity on the fronts of accessibility, independent living, and in-home services was easily achieved. However, activists for the disabled recoiled from the medical model of personal service out of fear that public payment streams requiring initial medical approval would result in agency hiring, supervising, paying, and firing of personal attendants, thus removing control from the disabled. These activists were clear that the personal dignity of individuals using personal services depended on their being in charge of the service—and the attendant as well—in a normal employer-employee relationship.

Whereas activists for the disabled generally were themselves disabled, and so spoke from that perspective, most activists for the aging were the “young” aging—the caregiver generation in their fifties and sixties. They lobbied hard for assistance for the caregiver—respite services, support groups, chore services. Relief for her plight was paramount on their agendas. They naturally looked to the largest fund-

ing stream in the aging arena—Medicare—for relief. If this involved medical gatekeepers and agency personnel, that was fine. To further their cause in the media and legislatures they depicted the caregiver's lot in grim terms: a loathsome job consisting of tending to the most disagreeable bodily functions of a cranky and ungrateful individual who lacked the grace to die quickly and cleanly and couldn't be pleased by anything done for him or her at such great personal cost to the unpaid family member.

Understandably, the caregiver-as-victim concept deeply offended activists for the disabled. Nor were activists for the aging charmed by the scenario drawn for them by the disability crowd: a simple employer-employee relationship was not a welcome thought to kin caregivers. However, political realities dictate that these interest groups forge an agreement on this issue in order to influence policymakers most effectively.

Conclusion

THE DISAPPEARANCE OF THE FAMILY CAREGIVER will lessen, but not void, many of the ethical dilemmas now so troublesome. The kin caregiver is not the only person in an abusive situation. Paid personal service workers are often people without many choices—new immigrants (documented or otherwise), low-skilled American minorities, or students working part time. They are poorly paid, have few or no benefits, lack job security, and often receive little or no training. There is nothing inherent in the situation that requires this. Good wages, solid benefits, respect—these will draw into the occupation those people genuinely suited for it—not those who must rely on supplications to Almighty God to make it through their dismal days. ☸



Life-Portrait of My Mother. Oil on canvas by Mary Meigs, 1958.

Reproduced courtesy of the artist. Photo: Ann Pearson.

Response

Honoring Identity

Claudia George

Second Opinion: Tell me a little about your situation.

George: My training and experience have been as a nurse. But I've been taking a break from that and now work part time as an administrative assistant at one of the City Colleges of Chicago. For the last year, I've been taking care of my mother in my home. She has had a stroke, and she has Parkinson's disease, so she needs total care. She couldn't make a call to get help for herself in case of an emergency, so someone always needs to be in the house with her, even if she's sleeping. Someone has to help her do everything—including help her entertain herself, help her stay oriented so she doesn't get confused and frightened.

For years before this, I helped her while she lived on her own, with at least weekly visits and a lot of assistance around the edges. And on three occasions I lived with her and took care of her after surgeries with lengthy convalescences.

Second Opinion: You have a home, a husband, a teenage son, a job, and you care for your mother. When you are not caring for her yourself, you are making all the arrangements for her care. A nurse comes in two days a week and your mother goes to day care three days a week, and that enables you to go to your job.

George: Right. In the morning before I go to work there are at least two hours of work to do at home. On the mornings that I send my mother out, those two hours are needed to help my mother get up and get ready to go out. Then it doesn't matter what condition the house is in, because we're all leaving it. On the mornings when the nurse comes in, I don't need to spend time getting my mother up and ready to go out, but it takes two hours to get the house in order so that the nurse can function there.

Second Opinion: Your experience is relevant to many issues raised by Debbie Ward. What did you think of her article?

George: When I first read this article, I thought it said nothing. Her experiences as a nurse and caretaker are a reality I've had all my life, so I didn't

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find anything new. And I was bothered initially that she didn't offer any answers to anything, just a few suggestions at the end.

But the next time I read it, I had a totally different reaction. The paper is very gently raising some questions that I didn't recognize at first. The article concluded with three questions: "Is this fair? Is it just? And can we risk asking?" Those are really good questions. "Can we risk asking?" That's a very important question. You *do* risk a lot asking those questions. There's a big part of me that doesn't want to ask those questions because they would disrupt, challenge a lot of things, risk opening up anger. Ward discussed the resistance to the questions, and I felt it as I read—tremendous resistance to raising those questions. They challenge the realities that I operate on, which is very disturbing. I find it difficult even to think about the consequences she talks about—the consequences of having women, unpaid women, do most of the chronic care in this country. It's very disturbing to think that other cultures don't do it that way or maybe shouldn't do it that way and that there are better ways to do it. I think I have some very deep anger about this.

If you as a woman have accepted the role of a caretaker all your life, have devoted a lot of time to that work, and made sacrifices to do it (and you *do* make a lot of sacrifices), it's a large part of your identity. But if this is just one way of going about long-term care, if these are arbitrary designations, then you have devoted a large part of your life to something that maybe wasn't fair, wasn't in people's best interests, and isn't just. It's very disturbing. You expected to make these sacrifices, and it was supposed to be the right thing to do. I'm almost surprised that the article should affect me this way, because it's not as if I haven't thought about these issues before. I've thought about the extent to which my identity as a caretaker was neurotic or inappropriate. But maybe before, I was struggling with trying not to be a caretaker when it wasn't needed. There are times when a caretaker is needed. This article mentions children. Children need caretaking, and so do elderly, sick people.

Second Opinion: Perhaps it was a necessary choice for you because the alternatives were not good.

George: That's true. Our society doesn't offer other good choices. The article points out that society has made an *economic* decision about long-term care. I don't know if that's true. I hate to think that's all there is to it. And I'm not sure that ethics, politics, and economics are necessarily the right categories for the consequences. But Ward also discusses something more fundamental that underlies all those categories—people's assumptions and beliefs. People are uncomfortable with caring for the flesh. Anything associated with physically caring for people—flesh bodies with all their demands—makes people uncomfortable, and they denigrate it. She suggests that women have a lower status, because they're associated with caretaking. I don't know which came first.

This article does a good job of pointing out how women's unpaid labor doesn't count. That has been my experience. A friend once suggested to me that it would be fair if I got reimbursed for some of my time spent doing the caretaking for my mother. That's something that I'd never even thought of until very recently. But when I do think about it, it does seem unjust that all my work, my time, and my energy somehow don't count in the scheme of things. They don't have the same status as things that people pay for. My work is not as valuable as, say, a cash contribution. When I think about this, I do feel some anger. And sometimes it makes me question myself. Perhaps my own life and priorities have been misguided. It's very disorienting to think that the assumptions you've built your life around are maybe wrong or flawed, because then you feel your whole identity is in question.

Second Opinion: What are the assumptions that you've built your life around, the ones that led you to do this caretaking?

George: I've always assumed that it was worthwhile and valuable and important for me to put other

people's needs before mine. I guess that's it. It's a way of life. However, I've come to realize that you have to meet your own needs too. And that's difficult in my present situation. Debbie Ward imagines a society set up to incorporate elderly persons. You could care for an elderly person at home and still have *diversity* in your life. It's not that I now wish I had nothing to do with caretaking. It's just that if there were more supports, I would be able to follow up more interests than just one and have time and money and space and encouragement to do some other things. I'm sort of new at this—I've been doing it for only nine months. I don't know how it will be after two years, three years, four years, but I can see the number of things that I'm neglecting, things that I want to do, things that I should do. Practically everything is being neglected. I either have to figure out some way not to neglect those things or suffer adverse consequences. And I'm not sure it's possible . . . I haven't made a lot of progress during these nine months in finding extra time. I'm not sure it's there.

Three days a week, my mother goes to an adult day care program run by the Greek American Community Services. Her costs there are subsidized by the State of Illinois Community Care Program. Without this assistance, we wouldn't be able to make ends meet. And it works, too, because this day care is an excellent program, a place where my mother is among people who take the time to get to know her and who genuinely like her. There should be many programs like this, but there are very few. That support is invaluable, but I can picture there being a lot more. And it isn't only in social structures but also in people's attitudes. My friends have been very supportive, but I can't say that I know other people who have had an old person in their home. My son never goes into another house where there's

an old person. I know other elderly people are being cared for in the community, but somehow it seems so invisible. You are not a part of the mainstream anymore. The caregiving isolates you, because social events and people's expectations do not take it into account. Things are somewhat better when you care for children, because more people have or have had small children.

Second Opinion: Why did you decide to take care of your mother? What were the alternatives?

“If you as a woman have accepted the role of a caretaker all your life, have devoted a lot of time to that work, and made sacrifices to do it (and you *do* make a lot of sacrifices), it's a large part of your identity.”

George: My mother spends the week at my home with me and the weekends in her own home, part of which time she is cared for by a boarder there. Of course she could have gone to a nursing home. But I'm not comfortable with an institutional answer to anything. I find it intolerable to be subjected to bureaucratic or institutional solutions, whether at

a school or a hospital or a nursing home. My mother has had a difficult life, and she has done amazingly well in spite of the difficulties. She gave us a lot of love. I would be very uncomfortable if she were in a place where I didn't know that she would be well taken care of and feel safe. Another alternative, which my siblings favor, is for us to sell her house and use that money to pay for more care in my home or for an apartment for her with live-in help. I know that's an option, so in that sense I don't feel trapped. But I'm not getting support from my siblings because I've insisted that my mother be able to keep her own house, and that means that we don't have any money to work with. I feel that keeping her own home is critically important to her. A person like my mother who has had a stroke and who is confused and virtually unable to do anything for herself anymore needs to retain something to ground her, to give her some sense that she still has an identity.

People may not appreciate how important it is for people to hang onto their own home. My brother and sister don't feel that it's important; they think that I am foolish and needlessly self-sacrificing. But I see this issue as a very important part of care for my mother. Being able to see the inherent value of caring for a person in the context of her family, in the community where she is still part of the stream of life, is very much tied into being able to see how retaining a house would be critical for that person's psychological well-being. Maybe the lack of support for the one is reflected in the lack of awareness of the other. When you take care of someone, you have to pay a maximum of attention to giving that individual what he or she needs to keep the sense of being a person. Of course that's most difficult in an institution. I spend four to six hours a day most days taking care of my mother, trying to do things in the ways that are most suited to what she needs. Naturally, if she were in an institution with 50 other people, that kind of time wouldn't be spent. There should be ways to allow someone to keep her own house and still have resources in the community to assist with her care.

I feel that society's not having a larger vision about the importance of providing long-term care and not valuing the work that women do in caretaking might be connected to a lack of awareness of what is needed to help people retain their own sense of importance and individuality.

Second Opinion: Are there any rewards in this work?

George: There's the reward of feeling that you are able to provide an optimal situation for a person you love, to make that person's life as interesting and as comfortable as possible. My mother still retains her personality, and she's still enjoyable to be around—that's rewarding. I would not be able to do this if I had a parent who was hostile, combative. There's a reward in realizing that it's still possible for individuals and families to have some control over their lives and not have to give over their control and

power to impersonal institutions, no matter what befalls. There is the reward of feeling connected to the people who have been supportive—my husband, for example.

Second Opinion: Do you feel any spiritual or religious motivations for this caretaking?

George: Yes, and that's also rewarding—to be able to act on your values, on your deepest beliefs. I believe that we all need recognition and love up until the day we die and that we are called upon to provide this for each other. And that it is through this love that we experience the fundamental goodness and unity of life.

Second Opinion: How do you feel about obtaining respite care?

George: I identify with women who express resistance to getting respite—they want to be the ones doing the caretaking. That's another fuzzy area having to do with your identity and what you take pride in being. If things were restructured and you didn't have to make the sacrifice, you'd have to reinvent yourself a little bit, learn how to picture yourself differently, which is threatening. But some of the resistance to respite care is because the alternatives are not good ones. You're going to resist having other people care for your child unless you're convinced that these people are not only responsible but will give quality care to your child. And I think that kind of situation is harder to find for disabled or older adults. We have been extremely fortunate to have two excellent nurses who come to my home to take care of my mother while I'm at work on the two weekdays she doesn't go out to day care. I don't know what I would have done without them. Joyce began taking care of my mother in the hospital right after her stroke and has continued to care for her ever since. She is wonderful with my mother. She sees and enjoys her as a person, and my mother loves being with her. They have fun together. I am happy to go off and leave my mother in her care.

Debbie Ward talks about choices: If people are given a choice between home care and institutional care, they'll choose home care. But that's a false choice. There could be a third thing—home care with support. People are reimbursed for institutional care and not for home care. That is ludicrous.

Second Opinion: That relates directly to what Ward says: The unpaid labor of women is supporting this society, and nobody wants to look at that because they don't want to pay for it. They're calling it "free," because they're not burdened.

George: You are pushed to add and add to what you are doing, as though it wouldn't mean that you are going to have to stop doing other things. But it isn't possible. You just can't do it.

Second Opinion: Would you say that the pressure to do more and more is being placed on women by people who are removed from the reality of caregiving?

George: Yes, and this has been an issue between my siblings and me. We are all trying to provide what we each think is best for my mother, but we have very different ideas about that. As the one who is giving day-to-day care, I need to do it in a way that makes sense, that I feel good about, that I feel is meeting my mother's needs. Otherwise I can't do it. If you didn't feel that you were providing what the person needed, you'd have no motivation whatsoever to do this. You can't just tell someone, "Do this care for this person, but do it the way that I say it should be done." To have the heart to do it, to get any kind of reward, you have to be able to do it the way you think is right. There's probably a larger application of that in the issue of how to support people who are

giving care to elderly people at home. There won't be a single formula that works for every person. You have to be able to support the caregivers with things that they feel are important for the person they are caring for.

Second Opinion: It seems to me that what you have taken on yourself is to be the voice for what you perceive to be your mother's needs against, in this case, your siblings.

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George: I think that people always have or should always have a voice. People can be very disabled in a lot of different ways and still have the right to a voice. Caregivers try to intuit the voice of the person they care for. Often if they've been close to that person, they can do it successfully. But if there's a difference of opinion among people about what the person would want, there needs to

be some recognition that whoever is doing the care should be listened to and supported.

This makes me think again about something that is part of the anger I'm feeling—the lack of recognition. Some may say, "We'll just pay for help here and get this done," but I know it's not so simple. There is actual substance to what I am doing and how I am trying to do it. It can't just be substituted by paying somebody else to do it. The needs that I'm seeing are real, and the benefits of trying to meet those needs are very tangible. It takes me two hours to get my mother up. What makes me angry is the lack of recognition that that's valuable, that it takes time, and that you can't always just hire somebody to do it, whether in an institution or at home. I'm not saying that you can't get help. I'm saying that there's a lack of recognition and appreciation for what women do, what caretaking people—who are

mostly women—*do*. And if legislators think you can replace that care with institutionalization, that institutionalization is the ideal solution to the problem of long-term care, they're wrong. It's amazing to think that someone could have so little appreciation for what it is really like and that something so real to me could be so invisible to people who are making decisions and who have money and power. When you do it, you see.

Second Opinion: Caregiving has an emotional content. For example, when you give a person a bath, which itself requires a certain amount of time, you're not just accomplishing a task; you're handling a person. You wouldn't dream of plopping a baby in a tub and scrubbing it—you put the baby in the tub, you tickle him or you give her little toys—you try to make it a pleasant experience. In institutions that aspect can be completely overlooked and overridden by time concerns. The tone of the society is changed over the long haul.

George: You're bringing up an important point. It's more or less understood that we need to make a caregiving investment for children, but people don't acknowledge this need for older people. The voices of elderly and confused people are overridden because they are powerless.

Second Opinion: Children have a future, and the elderly are "on the way out," so why bother? Is that part of the picture? Also, elderly people can be difficult.

George: Toddlers and two-year-olds can be difficult. They can be impossible and frustrating. But you basically stay positive. Maybe it's because you see the improvement. You see the growth and the

improvement that you don't see in an older person. But one thing has been made very real to me: if you spend six hours a day watching and listening to a confused older person, you are going to appreciate the core of rationality in that person. If you don't know the person or his history and he makes an off-the-wall comment, it just sounds crazy, confused. You write the person off; he doesn't make any sense. That may be a problem for my siblings, who aren't with my mother all the time. If you come from out of town for an occasional visit, it's much more difficult to make sense out of what she says or to feel that this is a person who still has the right to make decisions about herself. Although what my mother says now is confused, it's not lacking in foundation. She's drawing on her entire life experience all mingled together. And the incoming stimuli are confused. What she is hearing on television and seeing in the periphery of her vision becomes part of what might be happening right there, to her. She brings in past experiences as though they were currently happening. When you sort all that out and take that into consideration, the judgments and comments are very appropriate. When you watch it unfold like that, you do not feel like writing her off or saying it doesn't matter *where* she is. That's not correct.

The anger I was talking about earlier may be largely just this: the sense that something so fundamentally important to me, something I've devoted a lot of time and energy to in my life, is so undervalued and unsupported and unappreciated by my own family and by society at large. I believe that a lot of the pain and problems in the world come from ignoring people's needs—not only their physical needs but their needs to be looked at as individuals and to have others respect their feelings. ☹

Response

Recognizing the Caregiver

Joyce Blackwell

Second Opinion: Could you say a little about yourself and your work?

Blackwell: I'm a CNA, a certified nursing assistant. We assist the nurses in explaining things to the patient, talk to the nurses, and tell them what needs to be done for their patients. We are the ones who take care of the patients, have personal contact with them. We clean them up, dress them, feed them, take them to activities. We're always here for them. If a patient has a bedsore, we have to report it to the nurses so they can take care of it. I work in homes, hospitals, extended-care hospitals, and hospices, and I also do private duty. I've been doing this for over eight years.

I'm from Jamaica, but I received my training in the U.S. Before I came to the States, I usually took care of children.

Second Opinion: How did you react to Debbie Ward's article?

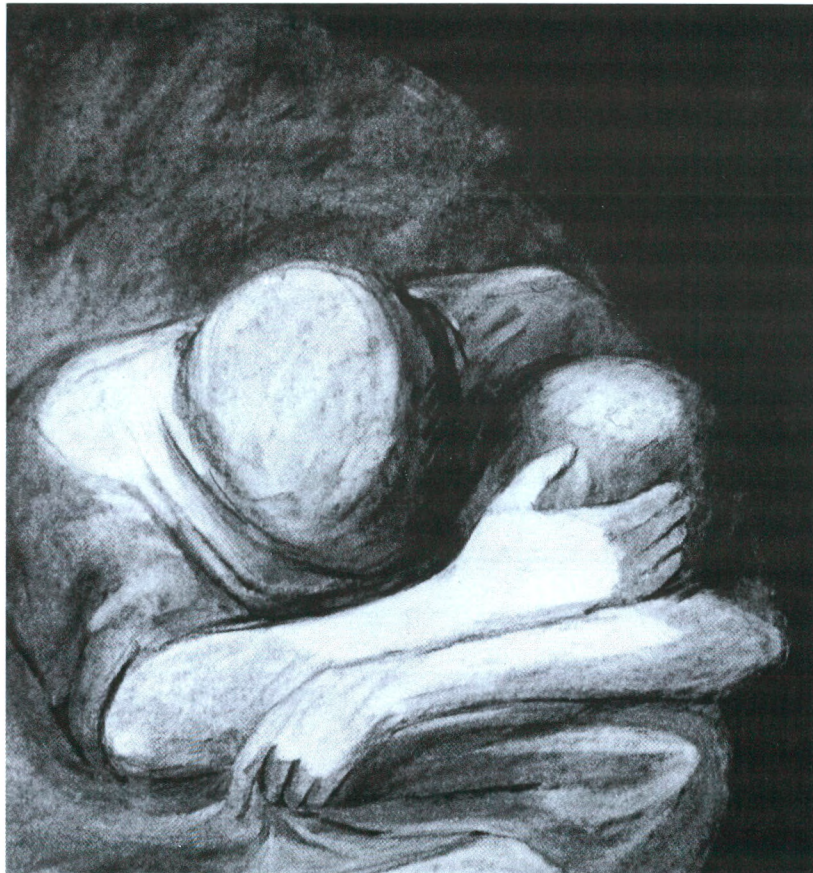
Joyce Blackwell is a certified nursing assistant who works in a nursing home and also does private duty in Chicago, Illinois.

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Blackwell: Her description doesn't match the way I look at what we do. When I go to work, I like to give of myself. That's why I prefer private duty: I feel that I have done something for someone, I can be there for that person, I can try to do what that person needs. If you work in a facility where you have 8 or 12 people to take care of at one time, that's hard. You don't feel fulfilled when you're done, because you don't give as much as you would like to. You come away feeling frustrated. You think about the things you didn't do or get a chance to do, things like holding someone's hand or giving a glass of water. When you take care of one person, you can do that. It makes you feel good.

Second Opinion: Would you say that's the main reward of this work?

Blackwell: That is my reward. When you give, you feel good about yourself. You come home, and you can relax—you know that you have done a day's work. I don't like to know that somebody didn't get something that they needed, because these people depend on you for their needs. Most of them can't do for themselves. Patients with fractures or diseases like Huntington's depend on you to do for them. I



Embrace. Charcoal on paper, 1988.
From the series *Bearing Witness*, by Boston artist Michael David.

Reproduced courtesy of the artist.

had one patient with Parkinson's disease so bad that it took almost an hour to feed her. You say to yourself, "What if I don't have that time?" How can you feed a meal to a person in that condition if you have 8 or 10 other people to take care of? There is no way that person can get enough food.

Second Opinion: How would you explain the source of your desire to give of yourself?

Blackwell: I think it's the way I was raised. In Jamaica we don't have nursing homes. We take care of our own parents and our own families. You can always leave your child with a neighbor or another person, because everybody in the community helps each other. It's always been that way for us. We take care of our own, and we do for others. It's not a matter of money—whether you have it or you don't. It doesn't matter.

Second Opinion: Debbie Ward notes that in the U.S. that type of work, if it's done in the family, is usually done by women. Is that also true in Jamaica?

Blackwell: Mostly women do the work of taking care. But families are so close that it is really done by whoever is home, whether it's a father, a grandmother, a cousin, or an aunt. If one person has to go to work, the next person at home is going to do the caregiving.

Second Opinion: You said that you and Debbie Ward looked at some things differently. What would be some instances?

Blackwell: I don't look at my work as just getting paid for a job. When I go out to work, if I have to

do something, pay or no pay, I go ahead and I do it. If I do something and I'm satisfied and the person is satisfied, I am rewarded. I don't look to the person that I do something for to give to me.

I have been blessed in so many ways—there's got to be some reward from somewhere. At any of the jobs I go to, I give these people the best of my ability—whatever I can give, I give. No matter how hard it is, how tired I am, I don't want to pass that person calling for a drink of water. And just because I'm rushing to go somewhere else doesn't mean I don't stop and give that person a glass of water. I don't want to feel guilty about it.

Second Opinion: You don't share with Debbie Ward the idea that the work is undervalued or underpaid?

Blackwell: The work is undervalued and underpaid. But that doesn't mean that I cannot go out and give of myself too, without looking for something. If I have to take care of somebody who can't pay, I will still do it. But in a facility some people feel you are there just to do the dirty work. They know that the job does not pay well, but they don't appreciate the hard work that you put in.

Second Opinion: Do you find this among people who are running the facility or among the people that you care for?

Blackwell: Mostly the people that are running the facility. The people that you care for are paying, and they are paying a lot. I feel that they deserve to be cared for properly—for the money that they put out. We are the closest to them. We see them, we touch them. All the nurses do is pass a pill. If we report

**"All the nurses do is pass a pill.
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something, the nurses will act on it, but that's all the patients see of those nurses. The doctors come and they may write in the chart, but that's about it from the doctors. Patients see doctors once in a while. We are there 24 hours a day, and everything is thrown at us. I've been a waitress, and I've worked other jobs too, and this is the most stressful job I know of.

Second Opinion: Ward points out that many poor women are stuck caring for their parents or their spouse. Do you see that at all as society's responsibility?

Blackwell: It's a responsibility of all concerned. It's a responsibility of the family to decide what to do with that person. Sometimes people don't know how to go about these things, because when you're poor, you stay that way. How do you find a way to help your parents? Maybe you don't know where to turn. That's why there are churches and community groups—places where people can get help.

Second Opinion: Do you see this at all as a government responsibility?

Blackwell: It is a government responsibility in this country. Because a lot of these people really work and put into the system so that they can be taken care of in this time of their life. So it's right for them to get that care.

Second Opinion: What about state-run nursing homes?

Blackwell: They're not good, but they're better

than nothing, better than having the people walking up and down the streets. Some are deplorable—the stench alone will kill you. But how about your family—your mom or your dad—walking the streets and eating out of the garbage? It can't be any worse than that. The government needs to start looking into the situation of poor people, because a lot of these nursing homes are built just for the rich. If you can't pay, you have nowhere to go. Very few nursing homes take Medicare.

I don't think the government is doing enough of anything. I'm not saying that the government shouldn't give help to other countries. I'm from a Third World country, and I know we need help. But what about the people *here*? They have needs. Politicians look for the poor person's vote, but afterward nothing gets done.

Second Opinion: Ward thinks one reason people don't want to deal with this issue of caring for the elderly is that they want to deny the reality of getting old and dying. What do you think?

Blackwell: Whether people think about it or not, this is what's happening. There are a lot of seniors in this country, and they need care. If you're working in a hospital or nursing home, especially a nursing home, you know that people go there to die. The death of a special patient that you care for and really get close to is a sad moment—it's like losing one of your own. You can't let it affect your life because other people need you. You just have to . . . let go.

Last year a lot was going on—people were getting hurt in nursing homes, patients were getting

“These people get old,
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They go into a nursing home,
but they don't want
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They *always* want to go home,
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they forget—that they
have a home and
want to be there.”

badly treated by nurses and aides. Sometimes people bring their problems to work. Only poor people do this kind of work. And they have their children who are having problems and who are giving trouble at home. They come to work with all this frustration from home and have to deal with this bigger frustration. That's double trouble.

Second Opinion: Do you think that better pay, better working conditions, more staff would change this?

Blackwell: That would help enormously. At least the workers wouldn't have to feel so degraded and so empty. This work is not fulfilling for some people, but it's what they have to do to live or to get by; they have to hold onto it no matter what. I work in a nursing home, but I also work in hospitals and in homes. I'm with different people, inside and outside of my regular job. When you work in one place, it can get to you. You ask yourself, "Why me?" or "How did this happen that I have to be doing this?" or "Where are the families of these people?"

Some families just bring the patients in and put them down and don't turn around. Once a month or once every three or six months they may come back, or they'll call and say, "I'm out of town, so I'm calling to see how my mom is doing." Some families come in and expect you to give the world for their mom or their daughter. They expect this of you, and you wonder, "How come you couldn't do it, but you're expecting it of me?" They are trying to get rid of their parents, to put the burden on somebody else. It's not that they can't afford it; with the amount they spend to keep these people in a nursing home or a hospital, they could certainly have somebody come into their home and do the care. Some families reach the point where they really cannot manage anymore. But why expect from somebody else what you couldn't give yourself? I want to say, "Hey, I'm only human."

Second Opinion: I wonder if this expectation has anything to do with *their* sense of guilt.

Blackwell: Always the guilt—it's just killing them. They could do better, but they chose not to, so they have to take it out on somebody. They take it out on the caregivers. You say to yourself, "Why does he or she, instead of taking care, find a caregiver to abuse?" It's hard on the family member, but instead of working with the caregiver to make it easier for everybody concerned, they make it harder. They cause stress. Most of the time the patient is right there listening. One lady said to her son one day, "Why do you have to talk to the aides like that? Do you realize that when you do that and you leave, they can do anything to me? I am the one that pays when you are gone." Why would the aide care if she doesn't have a heart? You have to have it inside of you, to know that this could be your mother or your sister or your grandmother.

Second Opinion: Is that the feeling that you take to work?

Blackwell: Yes, because that's *all* I have inside of me. All I can *do* is just keep the faith and know that I am doing what I am doing because I have a mother and a father. None of us knows the position we're going to be in—I don't know what's going to happen to me either. These people get old, but they didn't ask to. They go into a nursing home, but they don't want to be there. They want to go home. They get up in the morning, and they don't know where they are. "Why am I not home?" They *always* want to go home, as long as they can remember. And that's the *last* thing they forget—that they have a home and want to be there.

Second Opinion: Is it helpful to the staff when a family member comes to the nursing home to visit?

Blackwell: It's wonderful. We feel so good about it. You say to yourself, "This person really cares about their mother or father. They care, but they just couldn't manage." The son of one of my patients is there every day. He does her laundry, he takes her

out, he does everything. He does not come complaining that this should be done and that should be done. He does it himself. You want to say, "Excuse me, I'll take care of that. I'll do it." But his attitude is "It's all right. I can do it." It makes you feel good. You know he couldn't help the situation.

Second Opinion: Claudia talked about going to the hospital after her mother had the stroke. She was depressed and overwhelmed, but she said your presence made a tremendous difference. How is it for you when you go into a patient's room?

Blackwell: I walked into that hospital room, and when I looked at Claudia I saw a daughter who was very concerned. She looked like she was lost and she wanted to do for her mother. She was so tired, and she didn't know what to do. I thought, "This lady needs some sleep. Maybe I can do something." I decided that if she saw that I could take care of her mother the way she would want to do it, maybe she would leave her for a while and get some rest. I started to take care of her, and I told Claudia to lie down. She said she wasn't going home, she was just going to get some rest next door on the other side of the hospital. That's when I decided that I would really put out and do for her mother because that's the type of care I like to give. And her mother never complained. It's always laughter, fun. I just do for her the way I would do for myself or my own mother. It has turned out so well. I enjoy being with Claudia and her mother, her whole family. I love her. I love her very much. If I go and Claudia can't pay me tomorrow, that doesn't mean I'll stop going. I am *going* to take care of her mother.

Second Opinion: How do you handle it when the

patient is difficult or you don't have a good feeling with the patient?

Blackwell: Sometimes it's hard. I try to work with the patient's mood. If I have a patient who's combative or really difficult to deal with, it's like being with a child—I take time out. Sometimes I find myself leaving the room in the middle of taking care of a patient. I'll leave for five minutes and drink a cup of coffee, just to get away for a certain time so I can go back and deal with that patient. Things can happen in an instant in that situation, and you have to be very careful because there's a lot of patient abuse. You have to give yourself time to cool off.

**"I understand why
some people would prefer
to be on public aid than to do
this kind of work.
You work and work
and get nothing by the time
you get a paycheck;
you just work your life away,
and there's nothing there."**

Second Opinion: If a family member is willing to help with some of the tasks of caregiving, that's an indication that your work matters. But what keeps you going when the value of your work isn't recognized?

Blackwell: I do this work because I don't feel qualified right now to do something else. If I decided to go back to school, I could change and do something else. Not everybody is strong enough to continue this work as they get older. But I would still do private duty no matter what else I did; I still want to work with the elderly.

Second Opinion: What do you like about working with the elderly?

Blackwell: [*laughing*] I have fun. I have always had fun with my patients. I have a patient who doesn't speak at all. She has Alzheimer's disease. When you talk to that lady, it's like you're talking to a child. She giggles, and she responds in a lot of different

ways. I take her for walks. I take her for drives in my car. We go out for lunch. We go to the park, and I show her the birds and the different things in the garden. We do so many things together. And she's always smiling. You know she knows what you are talking about, but she can't say "yes" and "no" or talk to you about things. But I just stimulate her by talking to her about everything. I talk to her about my children and ask about how many kids she has. Because I *know* she's hearing me and responding; she just doesn't come out and say the words.

Second Opinion: But you might decide to leave this type of work?

Blackwell: I want to be a beautician. I would go into a nursing home or the hospital or people's homes to take care of a patient. I don't want to give up my work completely, but I don't want to spend the rest of my life doing this physical type of work. I love this work, and there's a lot of enjoyment in it, but I wish it was more rewarding on the financial side. This job just does not pay, yet it's very, very hard.

I still don't understand why it's so low-paid. If you have a family of three or four or five, how can you do this type of work for \$4.85 an hour? The cost of living and medical costs go up, but this pay never goes anywhere. Three-cent raises—that's nothing at all. Some people have just this one job, but I work several jobs. I have to pay the bills, and I have to take care of my family. Still, I understand why some people would prefer to be on public aid than to do this kind of work. You work and work and get nothing by the time you get a paycheck; you just work your life away, and there's nothing there. When you're on public aid, you can get some money for the month, and you have a medical card so you can see a doctor. Family medical insurance costs a lot, but you can't afford to take a chance, especially when you have children.

What I do not understand is what happens to the money when the facility gets it. There aren't enough workers, and the pay is low, so where is the

money going? What is a three-cent raise? When that is offered to you, that's when you feel the frustration and everything inside you just wants to scream out because you feel like *nothing*. You ask, "What have I done to deserve this?" I know I come in here and I do my job. I'm sure I try to take care of these people the best way I know how and you offer me *three cents*? That's degrading.

And you can't take it out on the patient. They're not responsible. If the patient isn't satisfied with something you're doing, they can say, "I am paying you *thousands* of dollars for this! I'm going to report you to the office and make sure you're fired because I'm paying thousands of dollars and this is what I get or I don't get." You can't blame them either.

You feel that you want to give just because the patients need you, but you have to think of yourself too and *your* family. We need help as caregivers. We need help to find a way that will make the job easier for us and make things work for both sides, for the patients and for the caregivers.

Second Opinion: What things right now would make your work easier and make things better for the patient?

Blackwell: The state needs to check into a lot of these nursing homes to make sure they have enough workers. The *load* they are putting on one person is not fair. One person is supposed to have just so many people to care for. If you overload that person, how much can the person give? People end up with huge and terrible bedsores because you can't do what you have to do for them: turning them every two hours and cleaning them and taking care of them properly. That takes time, a lot of time. But if you can't take that load, no matter how good you are at your job, then your hard work counts for nothing. No matter how good you are, you can be replaced. It's not the quality of the work you give but the amount you can give in eight hours. Administrations should look at the quality of a person's work more than they are doing. You get no recognition at all.

Second Opinion: Most of the administrators have never done the work you actually do?

Blackwell: Exactly. Some are CNAs who got into nursing, and they understand what situations are. They understand the work we do and what we've been going through, and they sympathize. But how is a person coming from the office going to know what is right for this patient when I am working with the patient? I have the connection with the patient. The administrator has the education and so believes that whatever he or she thinks is right for the patient is what's right. But it's not so. The patient talks to *me*, and I do the care. The administrator does not turn the patient over to look at a bruise or a sore, or to see what is going on with the patient. He or she just comes and says "Hi, how are you doing? Is everything all right? Was this done for you this morning?"

But I fed the patient this morning. I cleaned the patient up. I know how much the patient eats, what the patient likes. I know how much the patient weighs, and I know what to do for that patient. I *know* that patient. And you are going to say, "Why didn't you do this for this one?" or "This is what's supposed to have been done for this patient." No! You might be able to give a suggestion and add to what I've done, but that's it.

Second Opinion: Your knowing, based on experience, is not respected?

Blackwell: It's not respected at all. These people sit in the office, and they think they know it all. How

can a person who has never changed a diaper tell you how to put a diaper on? That's like telling you that you're not worth anything. I wish somebody would try to appreciate what we're doing, just *show* us that somebody cares about us too, not just the money they're getting out of these people.

"I'm blessed in so many ways
because I'm never
not able to pay for my light
or my gas or my rent.
There is always somebody
I have helped or
something I have done,
and I get a reward
from somewhere.
I feel that it's a reward because
God is looking out for me.
And I give thanks."

Second Opinion: If caregivers felt that their work was valued, would that translate into better care for patients?

Blackwell: That work should count for a lot. And yet maybe it's just me. Maybe I take too much on myself. I go to work, and I try to see that everybody is taken care of. If a patient is to get a bath, I would like to see the patient get a bath. You and I, we get up, we bathe every day. Patients get a bath once or twice a week. They are depending on me to give them that bath. I feel that they should at least get their bath once or twice. Just

give them that time. It's not fair just to leave them there because they can't bathe themselves. And if somebody else doesn't do it, then I feel that I have to go do it.

But you have to stop. You just can't keep going. Because if you do, my God, you're left with nothing, and remember, you have children and family to come home to, and they need you too. So many times I come home and I just want to forget. But how can you do that when you keep remembering something that wasn't done for somebody? You didn't give this person a glass of water or didn't brush this lady's teeth. I say to myself, "Why do I bring this place home?" But I can't go to sleep if I'm thinking "Oh, my God, I didn't do so and so today."

Second Opinion: If giving care is not valued, if the work women do in their home for their children or their parents is not valued, who is going to do it? There's a tendency for women to move away from that work because they don't want to do it all. They shouldn't have to do it all, but who is going to take up the slack?

Blackwell: I don't know what's going to happen. But it seems as if we are always the ones who are burdened with this. Always, all around. It's very rare to see a man burdened with this type of caregiving. With a couple of my patients, the men try to take care of their wives. But it doesn't last for long because they can't handle it. They are willing, but they just don't know what to do. At least they are willing, and they try. But men are weak. When you would fight to the bitter end, they can just barely make it halfway.

Some nursing homes have day care for the elderly. Some people whose parents do not require special care take them to the day care center while they go to work. It doesn't cost as much. If people wanted to have their parents with them, they could do that. You just wonder why some give up so easily. The most difficult situation is with Alzheimer's patients. If you are not prepared, it's very hard to care for a person with Alzheimer's. I can understand why you would put somebody in a nursing home for that kind of care. It would help to have more homes that give day care to the elderly. Families would be relieved of a lot of stress. They would be away from that person for a certain number of hours, so it wouldn't be so hard on them.

We have to find a way to take care of the people who cannot afford to pay. We have to do something for our neighbors, try to work as neighbors and help each other. That's what I notice here in the States: People don't help each other out. Everybody's going in their own direction. And so many people out there need help. What if we have a family who would fix a meal for an elderly person and take it to them? You don't have to know that person. You just know that the person is housebound and not able to do it. Or

you have a youngster you can send to the store to pick something up for this person. That's a way of teaching how to care, how to give. This is such a big country and there are so many people out there that *need*, but we're just looking out for ourselves. How this happened I don't understand. I wish we could have communities where people knew each other and helped each other out. The church really helps—the church is still the main post. It's church people who go to the nursing home and bring the patients cookies and dinners—not the families but church people. A lot of times I ask, “Is this from your family?” They say, “No, it's from the church.” They send flowers and gifts, and they come and visit. They make a *big* difference. Oh, do they make a difference. A lot of people there have never been married. They don't have families. Nobody comes to see them. *Nobody!* They just sit there looking. And it's hard. And that makes you think, “How did this come about?”

I'm glad that so far I'm still feeling good about myself, working in this field: a single parent with two boys, trying to bring up and school two boys. But God will provide for me. I'm blessed in so many ways because I'm never not able to pay for my light or my gas or my rent. There is always somebody I have helped or something I have done, and I get a reward from somewhere. I feel that it's a reward because God is looking out for me. And I give thanks.

I work hard, but sometimes you work hard and it still doesn't turn out. I hope that in the future something will be done so that everybody doing this kind of work can feel satisfied and fulfilled. It's not getting any better, and it's going to get worse. Because we have so many elderly, we need people who are going to care. With so many divorces, whatever we do, we're going to have single parents. And if your children turn away from you and are not there for you, who do you have?

I just pray, because I don't see anything getting any better. I pray for my situation, and I pray that I will be able to continue to give as much as I can until I can't do this anymore. ☹



Woman Thinking. Oil on canvas by William S. Carter, 1981.

Collection of Walter O. Evans.

Response

No Room for Hierarchy

Deborah Flemister Mullen

IT IS VERY POPULAR TODAY when speaking of human community to speak in terms other than those that signify hierarchical relations among people and within institutions. Cultural assumptions and value judgments pervade such language and may offend others' beliefs, social customs, and traditions. For decades, the language of hierarchy has been under widespread attack from women, African Americans, and other marginalized groups, sensitizing many Americans to collective and institutionalized forms of discrimination. Words like *superior*, *inferior*, *sub-*, *higher*, and *lower* convey a conception of social relations as hierarchical, in which people are assigned ranks from highest to lowest. Social discourse on matters of race, gender, and class is often coded in the language of hierarchy.

A visual complement to the language of hierarchy is the pyramid. Those motivated by a notion of rugged individualism often have one goal: to get to the "top" and, no matter what the cost exacted from

self, family, and society, to stay there! The ethic of individualism leaves little room at the top, especially for those who are believed to be inherently inferior.

Debbie Ward's "Women and the Work of Caring" deals explicitly with those at the bottom of the pyramid. Ward invites the reader into a conversation begun with herself as a young home health aide—one that obviously continues to stimulate her thinking as a researcher. With personal story and anecdotes, she begins by sharing the reasons she entered home health care and the process by which those early experiences developed into what she calls "my lifelong career interest—the caregiving work of women." Her methodology typifies the kind of thinking often engaged in by ministers and others in theological education as we try to integrate knowledge gained from theory with knowledge gained in practice. It is a methodology that values experience in relation to academic inquiry and sets disciplined research and study in a context of practical knowledge.

What does it mean for Americans that our cultural assumptions and economic, political, and social institutions have fostered exploitation of those whose gender, race, and class or economic positions in the pyramid have resulted in their becoming the

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culturally *accepted* and *expected* caregivers? As an African-American woman whose vocation and study of religion in America direct my attention toward such questions, I am encouraged by Ward's intentionality in uncovering some of the systemic barriers faced by low-income women and women of color who provide long-term home health care. She is right: these are the women who accept the positions others neither want nor want to pay for. Very little dignity is assigned to the work these women do. Ward suggests ways to address the issues of fiscal and structural change in the for-profit health care industry, to assign real value to caregiving, to pay equitable wages, to overcome public reluctance to deal with long-term care. She strikes to the heart of the debate when she asks whose job it is to care and who is accountable for the conditions under which caregivers work.

Is the Christian faith tradition a resource for taking up these questions? Can the values and ethical warrants of faith serve as a catalyst for thinking beyond the ranking of persons and for helping the least powerful to become agents of their own transformation? Can care be honored as a vocation?

The Christian faith tradition has been an extraordinary corrective to unjust social orders. My own consciousness, convictions, and sense of vocation have been shaped by this tradition, in spite of its human failures. It provides an alternative vision of a more inclusive social order and a source of hope for those who feel demeaned because their work is not respected. History, including the contemporary experience of African Americans and Christian feminist women, offers ample witness to social trans-

formation based in the ethical understanding of the Christian faith tradition.

The circle is an apt symbol for the social order so transformed; it replaces the pyramid and its hierarchical relationships. A symbol of inclusion and community, it is generally accepted as an alternative icon for women and men of faith, thanks in large

measure to the insistent voices of many feminist and womanist women of the late twentieth century.¹ As a symbol free of hierarchical trappings, it provides an open "space" for imagining more wholesome and supportive relationships among diverse people.

At present, violence is decimating the youthful leaders of the next generation. Disaffection is growing as increasing numbers of us are unable to support self and family. In such times, it is tempting to glorify the past. There was a time in our history as a nation when we did care for the frail and de-

pendent members of our families, and that caregiving was valued. Women exercised little choice, however, over the particular caregiving that fell to them. It is indefensible to justify social customs and patriarchal traditions that perpetuate the exploitation of women as caregivers. Ward has made that clear. At the same time, the communal values embodied in caregiving work need to be retained and shared. In the past, institutional long-term care was the exception. Home-based care was preferred by most, even if it meant "bringing someone in." Those "brought in" were often women already performing domestic service in the home or community. African-American women and other women possessing "gifts" of healing and nurture fulfilled those communal and family responsibilities. Many felt a

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“calling” or vocation to such service, growing out of their particular cultural values, faith traditions, and sense of social responsibility.

Debbie Ward asks how we can reconcile our professed wish to be a compassionate and just society with political and economic realities that exploit people already marginalized by gender, race, and class. Her efforts to level the assumptions that support the ghettoization of women’s work in chronic care and that perpetuate forms of structural discrimination against women of color and low-income women are a critical intervention in at least two ways. First, Ward is in a position as an educated, professional woman to risk upsetting the powers

that be by voicing her critical observations. The women whom she champions stand to benefit from having her as an advocate. Second, Ward’s article is a call to action to other health professionals, ministers, policymakers, and all whose lives are affected by the burgeoning demand for compassionate and competent long-term home caregiving. There is room for consciousness raising, community building, and political action to reconstruct human relations along more humane lines, lines that include and foster relationships rather than exclude and further marginalize both the gifts and the necessary work of caregivers. ☸

NOTE

1. *Womanist* is a term of contemporary theological, historical, and literary discourse coined by African-American women attempting to construct and reconstruct a voice and presence from the long-neglected experience and spiritual wisdom of African-American women. See the writings of Katie Canon, Jacquelyn Grant, Delores S. Williams, Kelly Delaine Brown, Zora Neale Hurston, Toni Morrison, and Alice Walker to gain a deeper appreciation of the contributions womanist scholars are making in their fields.



Autopsy. Sanguine crayon on pale green paper by Hyman Bloom, 1953.

Collection of the Whitney Museum of American Art, New York. Purchase, 54.18.

54½ x 37½ in. (138.4 x 95.3 cm.)

Our Bodies, Our Families

The Family's Role in Organ Donation

Charles J. Dougherty

THE CORE OF CONTEMPORARY EFFORTS to secure cadaveric organs for transplantation is the Uniform Anatomical Gift Act (UAGA), which was intended to create a voluntary opt-in system of donation based on the choice of individual donors. Part of the motive of the 1968 UAGA was to reduce the family's role in donation by direct appeal to individuals who, while alive, could designate through donor cards that their organs be used for transplantation after their deaths (Naylor 1989:46).

But the UAGA's individual, voluntary, opt-in approach has failed—on three accounts. First, it has failed practically. The UAGA process has simply not produced sufficient organs to meet demand (Spital 1991:1243). In one sense, this may be an unfair criticism. Demand for transplantable organs has itself increased dramatically. With new surgical techniques and medical successes in combating rejection, the number of patients who are candidates for transplantations has grown. Given the powerful mixture of motives for transplantation—

humanitarian, scientific, economic—no single approach or combination of approaches for obtaining cadaveric organs may ever match escalating demand. In another sense, however, UAGA has failed, irrespective of increased demand, because the number of people who have signed donor cards remains small compared with the number of people who express a general willingness to donate their organs: although up to 80 percent of the U.S. population express willingness to donate, less than 15 percent have signed donor cards (Manninen and Evans 1985: 3112). In other words, as a method for securing cadaveric organs from those who have a predisposition to donate, the individual, voluntary, opt-in approach of UAGA has not been successful.

Second, the failure of UAGA was tacitly acknowledged when it was revised in 1987 to include *required request*, a mandate that hospitals assign some staff member to approach the next of kin to request donation of a deceased family member's organs. This revision, which places the family at the center of the organ donation process, was a response to the failure of the UAGA's individual appeal (Naylor 1989:52). In order to increase the number of cadaveric organs available for transplant, required request creates a system for obtaining organs even when a deceased

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individual has not previously opted in by signing a donor card. The family, then, is allowed to opt in on his or her behalf.

Finally, UAGA has failed because, in spite of its provisions, physicians almost always obtain family authorization for removal of cadaveric organs, even when the deceased carried a signed organ donor card (Naylor 1989:54; Spital 1991:1244). According to the UAGA, the signed donor card in itself provides the legal authorization for organ retrieval to proceed, but medical personnel are unwilling to rely on this authorization alone. Several commentators have offered interpretations of this reluctance (Bermel 1984:6; Overcast et al. 1984:1561). Some point to fear of litigation, the concern by doctors that surviving family members will sue them for removing a relative's organs without family consent. But no U.S. court decision or legislation has ever been adverse to a UAGA-authorized donation. If doctors are afraid of litigation, this fear has no foundation in fact. Other reasons cited for physicians' reluctance to proceed without family consent include the desire for a positive image in the community and the resentment some doctors may feel at being told what to do by the law. But undoubtedly, part of this medical deference to the family is driven by moral concerns—that is, by the conviction that the family has a legitimate role to play in decisions about donating family members' organs, regardless of what the law says.

Are there any good reasons—in this age of individual autonomy—to involve the family in these decisions? Should the family have any role in determining whether a relative's organs should be donated after death?

Why the Family Should Have a Role

FOUR CONSIDERATIONS SUPPORT THE CLAIM that the family ought to have a role in organ donation. These considerations amount to a rebuttal of the

claim that a body belongs solely to an individual and that he or she alone should have the authority to decide to donate cadaveric organs for transplantation.

The Family's Traditional Role

ONE DEEPLY INGRAINED FEATURE of our culture is the reverence we expect in the treatment of dead bodies. In American law and tradition, families have the duty to bury or otherwise control the disposition of the body of their own kin. Families also have the right, with certain legal exceptions, to determine if a deceased relative's body will be autopsied. As one court stated, for "religious reasons, habits of veneration, or moral sentiments," the family is generally responsible for its members' remains (Naylor 1989:43).

Several reasons for reliance on the family can be inferred from law and traditional practices. The first is purely functional—namely, someone or some agency must properly dispose of the body. Obviously, a person or entity other than the family could be assigned this role, and others have been. For example, after the Norman Conquest, English law charged the Church with the responsibility for interring dead bodies properly. Probably because of the plurality of religious congregations in the colonies, however, early American courts departed from the English tradition and named the family to this role. Clearly, the state or a state-sanctioned voluntary association could also assume this role. But relying on the family has certain obvious advantages. First, nearly everyone has a family. Second, most families feel some sense of responsibility toward a deceased relative. Third, the family is the entity most likely to know the deceased's intentions or values concerning the disposition of the body and to be motivated to act on those intentions or values. The family is therefore a most natural organization to discharge this function.

Next, family members generally grieve at the loss of one of their own members, presumably a loved

one. Their grieving can be eased as they exercise control over the funeral and burial in ways consistent with family values and traditions. By contrast, grieving can be exacerbated if some entity other than the family dictates the means of disposal of a relative's body. The family again is thus the obvious solution for controlling the disposition of a dead relative's body.

Finally, a legal right appears to have evolved giving family members the authority to determine the disposition of the bodies of their own dead. To protect a family's sensitivities against intrusion by others in these stressful moments, American law recognizes a "quasi-property right" of the family in the deceased member's body (Naylor 1989:48). In a sense, the family *owns* the body of its deceased relative. If this is a valid perspective, then the family surely should have some role in the decision to donate a family member's cadaveric organs.

Property in the Body

AT FIRST BLUSH, IT MAY SEEM ODD to think of the family as owning the body of the deceased. Scholars of jurisprudence are plainly uncomfortable with this legal concept, which many regard as a lawyer-created fiction designed to prevent mental distress (Naylor 1989:48). Would it not make more sense, it might be objected, to think that the body is owned by the individual and that its disposition at death should follow only the will of the individual whose body it is or was? To put the point in personal terms, if I own anything at all, surely I own my own body. Why, then, should control over the disposition of my body pass to others at my death?

Three important rejoinders are possible. The first is a metaphysical conundrum, a form of the well-known self-referential paradox. If I own my body, who is the *I* that owns this body? Either possible answer seems metaphysically odd. On the one hand, if it is I-without-a-body who owns my body, bodiless subjects must be assumed to exist at

least as owners of bodies-as-objects. This assumption is suspicious from an empirical point of view. Moreover, anyone familiar with the history of philosophical dualism and its multiple critiques in the modern and contemporary world appreciates the nature of the difficulty here. How, for example, are these two entities (I and my body) integrated into the unity of a single person?

On the other hand, if I as a whole person with a body own my own body, then the difficulty created is that either I am the thing I own or I own the thing I am. Either formulation seems paradoxical. Typically, things that are owned, even intellectual property, are separable from the person, separable as an external object that can be delivered to someone else or separable as a skill that can be performed for the benefit of someone else. But the body seems to be neither an object that can be separated from the person nor a series of skills that can be given or owned by another separable from the person.

One apparent exception to this observation occurs in slavery or such slaverylike conditions as indentured servitude, "wage slavery," and prostitution—and even in the circumstances of medical research subjects being paid to participate in studies. These conditions suggest the possibility that although I may not own my body because of the metaphysical paradoxes involved, my body can be owned by another, either as an object or as a series of skills at another's disposal. But two responses can be given to this apparent exception. First, slavery is an ethical abomination precisely because one cannot own another person's body without owning the person. While the "inner life" of consciousness may provide something of a preserve for freedom in even the most abject forms of slavery, property rights in slaves were to their whole being, not merely to their bodies or services. Other slavlike conditions differ from slavery on just this point. Although they may create debased personal and social relationships, the body is not owned; thus neither is the person. The second response follows. The ethical repugnance of slavery and other forms of "ownership" or control of persons disqualifies them from providing any in-

sight into the *proper* relationship between the person and the body.

Another problem with the claim that I own my body is practical. For example, individuals may well own their bodies and govern the disposition and use of their bodies while they are alive, but at death such ownership or control passes to others. Even if I do own my body, how do I effectuate my will when I am deceased?

Clearly, one vehicle for effectuating a kind of ownership and control over one's own body after death is through an advance directive (a written or verbal will or a durable power of attorney) that directs another person to dispose of the body as the deceased individual intended. This sort of agency through another is least problematic if it is based on a promise before death. A person empowered in a will or durable power of attorney may agree, for example, to have a friend's body cremated. Agreement creates moral obligation, other things being equal. But from a moral point of view, should the next of kin or any other person be bound by the will of the deceased if that person had no prior knowledge of the role specified for him or her in the will? What happens, for example, if the next of kin or executor finds the activity required by a will morally objectionable? Such considerations suggest that even if I own my body, I may not have the exclusive right to control it after death.

Third, if I own my body, do I thereby have the right to dispose of it as I please after my death? At first this may seem an odd question. Doesn't ownership entail the right to dispose of something as the owner chooses—the right to give it away, sell it, bury it, burn it, or immerse it in the sea? The assumption here is that ownership entails unrestricted control. But this is not always so. In fact, with many forms of legal ownership, the property owned cannot be sold or given away. Property can

be owned legally, but its use or disposition can be restricted in significant ways (Rose-Ackerman 1985:7; Andrews 1986:29).

Consider these examples. If persons own their bodies, they also own their body parts. But some body parts that can be given away cannot legally be sold—kidneys, for example, and other solid organs. If persons own their bodies, they also own their body functions. But some body functions that can be

given away cannot generally be sold legally—sex, for example. That children belong to their parents may be thought to create a relationship approximating ownership. Certainly, parents have a wide range of controls over their children's bodies and behaviors. But a number of laws also restrict what

parents can and cannot do with their own children. And again, children can be given away but not legally sold. Persons can also own the dead bodies or body parts of endangered animal species (for example, a stuffed bald eagle or an elephant's tusk). These properties too can be given away but not sold.

On the other hand, certain forms of property can be sold but not given away. When a business with creditors is going into bankruptcy, the owners can sell assets of the business but cannot give them away. When a person in a nursing home is "spending down" to qualify for the Medicaid program, he or she can sell assets but cannot give them away, not even—especially not even—to family members.

Other kinds of property also have restricted uses. An adult can own liquor but cannot sell it or give it away to minors and cannot consume it in many public places. A person can own a liquor license in a tavern but may not be able to sell the license even though he or she can sell the tavern. In many cities, a person can own a license to operate a taxi and can sell the taxi but not the license to operate it. A person owning a building subject to historical preservation laws may be required to maintain it in certain ways.

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Someone owning a lease to extract mineral resources from federal land must exercise that right or risk losing the lease. Finally, a wide range of municipal zoning laws and subdivision covenants both restrict and require certain uses of validly owned property.

In short, even if I own my body in some sense, and even if someone has agreed to exercise my property rights as my agent after my death, my right to dispose of my body may still be restricted and perhaps even ought to be restricted, just as uses of other forms of property are. It may be that I own my body but that the donation of my organs after death is properly restricted by the involvement of my family.

The Family and Our Social Nature

A MORE GENERAL CONSIDERATION that supports family involvement in decisions to donate organs of their deceased members involves appeal to the nature of the family. A first difficulty that must be faced, however, is definitional. What is a family? Though meanings vary across fields of law and across cultures, a standard definition in U.S. law identifies a family as “a group of persons consisting of parents and children” living in one household, or a husband, wife, and children whether they dwell together or not (Nolan and Nolan-Haley 1990:604). From an economic point of view, families can be seen as households that have traditionally protected their members from uncertainty and have provided a kind of social insurance (Becker 1981:238). Alternatively, families can be identified as groups that fulfill certain vital social functions, such as responsible reproduction, economic support, and emotional security (Lamanna and Reidmann 1985:218).

One of the most salient features of contemporary American families is their diversity. An aging population, new roles for women, changing sexual mores, and economic pressures have made the previously dominant nuclear family (mother, father, and children in one household) a minority

phenomenon at the end of the twentieth century. Today’s families include large numbers of adult households with no children, single-parent families, blended families of remarried adults and step-children, families with elderly members and multiple generations, same-sex parents with children, cohabiting adults with or without children, and various other arrangements (Copeland and White 1991:2; Wetzel 1990:4).

In the face of such variety, there is room for considerable skepticism about global characterizations of “the” family. Yet from a practical moral point of view, two important considerations make discussion of the family’s role possible in this context. First, nearly everyone can identify his or her own family. Though the boundaries between immediate and extended family often may be vague, people generally know where they belong as family. Second, in practical contexts like clinical medicine and direct social services, the changing character of the American family has been accommodated—not without problems, of course—but with quotidian success. When an attending physician asks for a meeting of the family to decide on the care of a dying family member, the family identifies itself for the occasion. When a social worker asks to consult the family on the proper locus of care for a disabled dependent, available family members assemble for the meeting and consult with key members who cannot be present. In short, despite the theoretical problems raised by the changing character of the American family, in practice, families are who they say they are. Typically, no further definition is necessary.

For most people, family relationships constitute their most intimate society. Moreover, nearly everything that can be asserted about the social character of human life can be said with equal or greater strength about the family. Thus if society in some form has a legitimate role to play in the disposition of individual bodies—and surely the law does—then the family may have a stronger claim on a role with respect to its own members.

Human social inheritance begins in the family

with the body itself. Each of us is the product of the union of two other bodies. Biological parents occasion our entry into society and our existence in any sense. Membership in the collective gene pool is specified by the genetic inheritance carried by the parental gene cells. Many families thus contain bodies with remarkable physical and behavioral resemblances. Furthermore, the practical support that the body needs is provided in most cases by the immediate family, regardless of biological relationships.

Family members often have the most intimate access to each other's bodies: bodies that have been borne of others' bodies, bodies that have given birth, and bodies that have made love. Families have bodies that have washed, clothed, nursed, and trained—and bodies that have *been* washed, clothed, nursed, and trained. In families, the flaws, vulnerabilities, and decline of bodies are revealed as in few other settings. In youth, illness, and old age, bodies are fed, groomed, and cared for by family members. Except for serious medical conditions, bodily injuries are ministered to by members of families. Even in cases of serious medical conditions, it is generally parents or those who stand in their stead who must grant consent for medical interventions.

Related points can be made about the socialization that fosters development of personality in children. Persons enter society through language, a language learned first and most intimately in the family. Persons also enter the broader society with a specific religious and ethnic identification, determined again by the traditions and practices of families. The family, then, is the locus for the establishment of the primary habits and dispositions that shape the values of family members.

Many of these points about children in relationship to their parent or parents are also true about parents in relationship to their children. Care for the bodies of children, cultivation of their personalities, and the general activities of parenting define central relationships in all societies. Parenting shapes adults as it shapes children. Subtler but equally important are the ways that families of adults shape each other.

The relationship in a family of two adults, for example, continually reconstructs each individual's sensitivities and habits, worldview and choices.

Finally, the family is one important locus in which social nature and individuality become most nearly intertwined. In many family settings, persons are free to be uniquely themselves, able, for example, to set aside many of the masks of public life and to reveal dispositions, aspirations, and vulnerabilities often hidden from others. In other words, the haven of families allows us to be our individual selves—for better or for worse. On the other hand, in families our individuality is most uniquely tied to well-defined social roles. She is a wife and a stepmother. He is a son and a brother. She is the granddaughter; he the uncle, and so on. Thus individuality and society are integrated in the family.

This description is not meant to romanticize the family. The unique environment of the family can cripple as well as liberate individuals. Socially, the family is the main vehicle for carrying not only the best of our moral and religious traditions but the worst as well—racism, ethnic prejudice, religious bigotry, and so on. Dysfunctional families can create and heighten personal adversities and pass on to future generations problems that range from the minor flaws of surplus anxiety to the deep tragedies of child abuse. Moreover, because families support human talent in different ways, rewarding and favoring certain talents over others, they are the source both of genius and of the cruel inequities of contemporary society. For better or worse, the family is at the heart of socialization.

The point of these observations is simple. The claim of individual autonomy is undermined—or at least reshaped—by acknowledgment of our social nature. The original UAGA goal of structuring a policy of organ donation chiefly on the principle of individual autonomy was a mistake. Organ retrieval policy must be shaped by some social considerations. Chief among these considerations is the primary society, the family.

The Family as Mystery

THESE POINTS ABOUT THE FAMILY and our social nature can be taken to a deeper level with the use of insights from philosopher Gabriel Marcel's thought (1984:19). According to Marcel, determining the appropriate role of the family in the donation of cadaveric organs is more properly a mystery than a problem. A *problem* involves an assortment of facts external to an agent regarding which there is some confusion or challenge. A person cannot get a car to start or cannot understand a bus schedule; these are problematic situations in which the difficulty, even if mental, is conceived as apart from the agent. The car is a thing that stands in need of repair. It can be fixed (or not) with little or no direct impact on the agent as a person. Plainly, inconvenience and cost may affect the agent. But the agent is not affected in his or her existence as a person. Similarly, although being unable to interpret a bus schedule may thwart an agent's intentions, the schedule for the bus is independent of the agent's needs. Presumably, with greater patience or training, he or she could interpret the schedule, as other travelers do.

But other sorts of confusions or challenges make an irreducible reference to the *person* of the questioner. This reference is clear in the case of deeply metaphysical questions. Who am I? How do I relate to my body? Why is there suffering? Why in *my* life? Can I hope for recovery, for redemption? No putatively objective answer responds to the manifest subjectivity of these questions. An equally irreducible element of self-reference is also present in many of life's practical choices. Should I accept this job offer? Should I marry? Should we try to have children? Should I become part of this family? Such choices are not independent of who I am as a person. Instead, these choices help to define or reveal who I am in a most intimate fashion. Such circumstances present themselves as mysteries, not problems, because they do not present themselves apart from selves.

Certain methods of approach are appropriate for

addressing problems, others for mysteries. For seeking resolution of problems, the general procedures of common sense and scientific method are appropriate. Moreover, objectivity is an important goal. But in the field of mystery, when one is faced with questions and choices that define the self, the resources of subjectivity are appropriate, including faithfulness and trust.

The relationship I have to my family or, rather, the relationships that shape who I am in my family are a mystery, not a problem. Each of us enters existence not in general but into a particular time and place and into a specific family which we do not choose and over which we have no control. Both choice and control increase as we mature to create and recreate families. Yet the horizon set by our initial families is inherited as defining, existential fact. And the persons who belong to us as family at any stage in life and in any arrangement define and reveal our most intimate selves.

Plainly, there are empirical and legal questions about family, marriage, cohabitation, adoption, inheritance, probate, and so on. These can be handled exclusively as problems. So can many of the issues of organ donation—so long, that is, as the subjective *I* is missed or dismissed. Analysis of organ retrieval policy can begin as a problem, with a legal focus on individuals and donor cards. But it cannot end there. To address these issues as problems without existential content is to lose the metaphysical framework of mystery that is the family.

When dealing with the body and potential transfer of organs from one body to another, reference must be made to deeper personal issues. How and why do I have this body? How is my embodied self related to others? If my body comes from others as a gift I neither requested nor deserved, do I "owe" gifts in return? These questions refer back to the self and to the mystery of its immediate and primary social context. They suggest that the family must have some role in the disposition of the body after death and in donation of the organs of deceased family members. This role should be shaped by a presumption—a rebuttable presumption—in favor

of the faithfulness of the family to its own members and of the trust individuals place in the choices families make on their behalf.

The Family's Proper Role

IF THE CONSIDERATIONS ABOVE ARE SUFFICIENT to show that the family has a legitimate role to play in the process of cadaveric donation, what should that role be? Certainly, I am not suggesting that the decedent's will concerning organ donation, when explicit and morally acceptable, can be disregarded or overridden by the family. Proper respect for individual autonomy should produce deference to the indisputable written or oral intentions of an individual expressed before death concerning the disposition of her or his body afterward, including donation of organs for transplantation. Obviously, there are moral limits to this; others cannot be bound by a decedent's will they regard as immoral. But as a general rule, the undisputed will of a competent adult should be followed in the transplantation arena, whether it effects a donation or refuses it. In these clear cases, approval by the next of kin or other members of the family is unnecessary, and any objections they may have should be disregarded. In the vast majority of cases, family members will take it as a moral trust to see that the unequivocal intention of their kin is respected.

Because of the rightful involvement of the family in these matters, however, the family should control decisions to donate when the decedent leaves no explicit directions or when the decedent's intentions are in dispute. For example, if the decedent left behind a signed donor card but a family member has evidence that the decedent had second thoughts about this choice, such evidence—if credible—is sufficient to override the written document. When there are disputes among family members—when, for example, some say a donor card is still valid, while others dispute its validity—these disputes could be resolved in one of two ways. Protocols could be established for appeal to an independent third

party, an ethics committee, for example, that would make a decision based on the credibility of the evidence produced. A more likely alternative is to adopt present clinical practice for reaching decisions for incompetent patients. Providers could defer to the family member or members thought to be closest to the patient, the ones most able to speak from experience about the patient's wishes or values. When this strategy fails to end family discord over donation, the remaining option is appeal to the courts.

In the event that the decedent neither signed a donor card nor left any credible written or oral instructions, the family should be free to choose whether to donate his or her organs for transplantation. Here, the considerations articulated above make the most practical difference. Authorization by the decedent while alive should not be necessary to effect donation, nor should the lack of an advance directive bar the family from refusing donation. In both cases, the family—not the doctors or the state—should have the authority to make donations from a body that is in many senses their own.

If this seems a tepid conclusion, simply justifying the current practice of required request, it must be pointed out that this conclusion is also consistent with a policy of presumed consent to donate organs. Under such a policy, when the will of a decedent is not known, it would be morally acceptable for the medical staff to approach the family and inform them that organs will be removed for transplantation unless the family objects, but that if they do object, the organs will not be removed (Dougherty 1986:105). This strategy is not meant to empower any one family member with veto control over donation. Consensus within the family should be sought, but when it is not forthcoming, the steps outlined above are available: third-party resolution, clinical identification of the "closest" family member, or appeal to the courts.

This approach is different in subtle but important ways from the required-request policy, which often puts the family in the awkward position of having to decide whether a newly deceased loved one

would have wanted to donate organs. The presumed-request policy changes the social burden of proof in favor of donation and asks only whether the family objects. Individuals could still write refusals in advance; thus individual autonomy would be preserved. In every case, the family would have to give passive authorization—that is, they would have to be given the opportunity to refuse donation. But they would not be asked affirmatively to choose donation. They would be asked only to acquiesce to a presumption based on a social consensus.

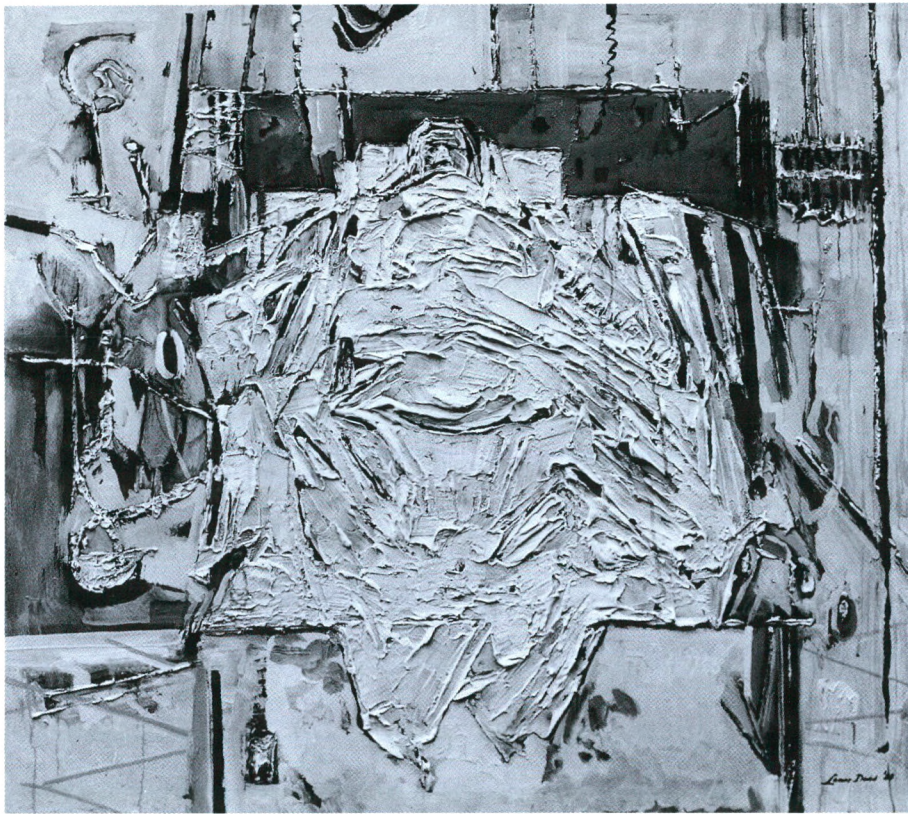
Nothing presented above argues in favor of a policy of presumed consent. I am simply pointing out that the role I have identified here for the family is consistent with a policy of presumed consent that grants the right of informed refusal by individuals and families. My own view is that, consistent with

other priorities, especially those concerning the resources society determines are appropriate to invest in transplantation, a policy of presumed consent would be morally preferable to the present policy. But that is another argument.

The point to be insisted upon is that the family has a legitimate role to play in the decision-making process about cadaveric organ donations. The UAGA approach, which hoped to isolate the individual from the family, was a mistake. The present practice of involving families better captures the moral realities of the family's traditional role in determining the disposition of the body. It is consistent with public policies that place limitations on ownership even if a person owns his or her body. And it more accurately reflects our social nature, a nature existentially rooted in the mystery of the family. ☸

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Awaiting. Mixed media on masonite panel by Lamar Dodd, 1983.

Photo: John Lawrence, Lamar Dodd Art Center, LaGrange College, LaGrange, Georgia.

The Selling of Organs, the Sharing of Self

Courtney S. Campbell

OUR SOCIETY CONTINUES TO CONFRONT a chronic shortage in the supply of transplantable solid organs, especially kidneys, livers, and hearts. Since initial successes with some organ transplants in the 1950s and 1960s, policymakers have struggled with how both to increase the supply of needed organs and to distribute organs equitably under constraints of scarcity. Patients, meanwhile, may find themselves on waiting lists for up to three years for certain transplants (primarily kidneys), a duration that proves fatal for some. In May 1993, for example, 31,303 persons were on waiting lists for transplants (Youngner and Arnold 1993). In 1989, 1,878 persons died while awaiting transplants (T. Peters 1991).

A procurement policy that has been hailed as “a potential solution” to the problem of insufficient supply is the development of a commercial market in organs (Denise 1985:1015). Conceived as an alternative to the *gift* model of procurement, in which organs are given and received, the *market* model

would permit buying and selling (or perhaps bartering and trading) in organs. We know that living persons can dispense with one of a pair of certain nonregenerating organs such as kidneys and still be healthy and fully functioning; hearts and livers, which a living person cannot do without, might be bought from relatives of a deceased family member. The organ market thus seems to hold out the prospect of alleviating to some extent the chronic scarcity of organs and thereby promises to save lives, a social good that few would dispute.

Yet, while important initiatives to increase organ procurement were proposed during the 1980s, particularly the federally mandated policy of required request (the routine inquiry made by caregivers to families of the deceased), proposals for an organ market were rejected and largely relegated to the margins of public discussion. In 1983, for example, a Virginia entrepreneur, H. Barry Jacobs, announced plans to begin an organ brokerage firm, a business that at the time was permitted by Virginia law. That permission, however, was quickly rescinded in eight states, including Virginia, and in the District of Columbia by federal and state legislation *prohibiting* organ sales. The National Organ Transplant Act of 1984 (NOTA) made it “unlawful

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for any person to knowingly acquire, receive, or otherwise transfer any human organ (including human kidney, liver, heart, lung, pancreas, bone marrow, cornea, eye, bone, and skin) for valuable consideration for use in human transplantation if the transfer affects interstate commerce.” In addition, the public image of an organ market was colored by disturbing reports, particularly from Britain, that persons in Third World countries, such as Brazil and Turkey, had sold their organs to brokers or wealthy patients. This led the British government to pass legislation prohibiting organ sales; such stories seemed to shift the moral imperative from saving lives to protecting vulnerable persons from exploitation.

The required-request approach has not, however, been the panacea envisioned by its advocates. We are still short of organs (by tens of thousands), people continue to die who otherwise might have been saved, and the number of donors has actually declined in recent years. Thus the 1990s have witnessed renewed attention to various financial inducements to encourage organ recovery, including cash payments for the organs of living persons and cadavers and reimbursement of burial expenses or death benefits to the families of the deceased. Moreover, arguments supporting such proposals often couple appeals to economic self-interest with issues of equity: virtually everyone involved in the transplant process—surgeons, physicians, transplant coordinators, hospital staff, for example—receives financial compensation “except the recipient, who benefits the most anyway, and the person whose organ is used” (Dougherty 1987:52).

I want to examine critically the ethical viability of an organ market and to determine whether procedures and modifications might be implemented that would achieve the desired benefits, namely, more organs for lifesaving transplants, without reaping some of the evils of the market system, including exploitation. Our current prohibitive policy toward an organ market, as contrasted with a regulatory model, may be difficult to defend by invoking such normative principles as autonomy, beneficence, or justice. However, we may see that the controversy

turns on much deeper dimensions of human experience by focusing on two related questions: What might be wrong with *selling* organs in a system of commercial exchange? And given that we allow certain body parts to be sold (hair, blood, sperm, oocytes, for example), what might be wrong with selling *organs*? At stake is nothing less than philosophic and religious conceptions of the moral significance of the human body. Moreover, insofar as the body is the principal medium for the revelation of the self, a sense of self-identity and integrity will be embedded in our policy affirmations. My critique of the selling of organs thus relies heavily on what is ultimately a religious sentiment that the self is to be shared with others in community rather than sold to strangers in a market.

Selling Organs

AN IMPORTANT ISSUE AT THE OUTSET is the moral rationale for an organ market. Such a market might be defended on two quite different grounds. The first, implicit in the suggestion that an organ market may alleviate or “solve” the organ-shortage problem, would justify such an approach in terms of its overall social utility. A second argument moves in the opposite direction, grounding an organ market not in social welfare concerns but rather by placing boundaries on the intervention of society in private choices. On this second account, the market is justified as an expression of personal autonomy and self-determination, irrespective of its social impact.

The social-utility argument may be challenged on several points. First, the social utility of organ transplantation generally can be questioned. If the primary ethical basis for health care is saving lives, society would do much better to reallocate the substantial financial, research, and institutional resources required for transplantation to preventive and basic care. This kind of social prioritization was enacted by the Oregon legislature in 1987 (distributing Medicaid funds originally allocated for 34 organ transplants to an estimated 1,500 pregnant

women and children for prenatal and basic care) and continues to be at the core of the controversial rationing proposals of the Oregon Health Plan. While this prioritizing arrangement has many commendable features, it raises no distinctively problematic concerns about an organ market. Rather, the critique is directed at the entire enterprise of organ transplantation.

If we do grant that organ transplantation is an acceptable, if not necessarily preferable, social practice, it nonetheless seems excessively optimistic to believe that an organ market would actually solve the problem of organ scarcity. Even strong proponents concede that the effect of an organ market on the supply of organs is uncertain. To be sure, any organ procured through this approach would increase the supply and possibly save a life. It seems quite unlikely, however, that 20,000 or so persons (or families of deceased individuals) would step forward over the next year and offer their kidneys or other organs for sale. Proponents have assumed that an organ market would not affect the pool of organs procured through donations and gifts—that a commercial and a gift model would operate on parallel tracks. Over time, however, the financial inducements of an organ market could completely subsume the gift approach, as economically strapped “vendors” felt they should “sell now” rather than “donate later.” Or it could lead to a decline in donated organs by prospective donors who experienced a kind of moral revulsion at “traffic” in human body parts.

Thus, the social-utility argument for an organ market raises a question about how many vendors would come forward. Yet if our real concern is to retrieve as many organs as possible so that we can rescue as many lives as possible, we should do more than rely on the whims and uncertainties of a market. Policymakers might instead opt for a method of presumed donation, in which suitable organs would automatically be retrieved on death unless the person had previously expressed wishes to the contrary. Such a policy has serious ethical problems, including whether presumed donation

shades into expropriation (“body snatching”) in the absence of a massive public education effort (Childress 1989), but evaluating such claims is tangential here. My main concern is to indicate that the appeal to social utility doesn’t provide sufficient warrant for an organ market, because other, more efficient and effective means could alleviate the organ-shortage problem.

The argument for an organ market from the personal autonomy and self-determination perspective does not, of course, take up the difficulty of whether a market will deliver what is promised. Rather, this argument is rooted in what essayist Michael Kinsley refers to as “the moral logic of capitalism” (1989:88), namely, that “if an exchange is voluntary it leaves both parties better off.” The market can also be seen as an expression of the liberal individualist tradition that affirms the moral freedom of persons to do with their bodies what they wish, free of interference by the state, so long as others are not harmed by the action. If that means dis-organ-izing one’s body by selling off a part of it, that choice should fall within the domain of individual freedom and should be valid whether or not society has 20,000 other willing vendors. On this account, the prohibition of an organ market appears to be an unjustified form of governmental paternalism and intrusion into private choices.

This argument, with its appeals to notions of individualism and self-ownership as opposed to the coercive powers of the state, seems to provide a stronger rationale for an organ market than does the appeal to social utility. Still, it is problematic even on its own premises. To begin, should limits be put on the kinds of organs sold? Suppose, for example, that an individual wanted to sell a vital organ, such as the liver or heart, perhaps to provide for his or her family, to pay for a child’s operation or education, or for any number of other reasons. The particular intention should not matter, because the individual’s choice to sell is the sole criterion of validity, lest a kind of paternalism enter in through the back door. No doubt we would think it a rash decision, but even so, an argument rooted in the

primacy of self-determination could not justifiably restrict *which* organs could and could not be sold.

Such a decision would nevertheless infringe compelling societal, not to mention familial, interests that, in my view, provide sufficient support for restrictions on selling organs when the immediate effect would be the death of the vendor. And, in all fairness, no one has seriously proposed that an organ market go this far. It seems to violate even the minimalistic moral logic of capitalism, in that while many persons, including the recipient and the vendor's family, would benefit in certain ways, one party to the exchange—namely, the vendor—would suffer a very substantial loss.

If a market can accommodate restrictions on what can be sold, an equally important issue is a concern about *who* can sell. In particular, an argument that affirms autonomous choice and the morality of “voluntary” exchange needs to consider the autonomy of prospective vendors and the conditions of voluntariness. The principal hurdle in this respect is that an organ market, like all other markets, would not be entered into equally by all parties, vendors, brokers, or buyers. Without further restrictions and regulations, then, such a market would most probably resemble other markets where commodities are bought and sold, and it might well be worse, because many buyers may be in an absolutely desperate health condition, and some vendors may be in a very difficult, if not desperate, financial condition.

In any event, some persons will be in stronger positions as they enter the market, and others will be in more vulnerable situations. One would expect, therefore, that exchanges in an organ market would be structured along the lines of rich and poor: access to the market would be conditioned not so much by medical need as by willingness to sell and ability to buy. In short, existing social inequities are quite likely to seep into the organ market, creating a condition rife with prospects for exploitation.

In this context, it seems entirely valid to ask, as one could in response to the stories of Third World

sellers alluded to above, whether a vendor's choice to sell is voluntary and autonomous or reflects a form of coerced decision incompatible with the autonomy rationale for the organ market. At the core of the idea of autonomy and free choice is that a person has available alternative courses of actions to realize his or her life plans. In testing the autonomous nature of a vendor's decision, we must ask what alternatives he or she has to achieve the pursued objectives—for example, to provide a needed operation for a daughter, as in one case in Britain involving a man from Turkey who sold his kidney for \$4,000.

Some proponents of an organ market have maintained that invoking concerns about the integrity of an autonomous decision reflects a vicious form of paternalism: it implies that economically vulnerable persons cannot genuinely exercise autonomy and thereby calls into question their qualifications for membership in the moral and political community (Humber 1985:24, 25). Prohibitions on who can sell are indeed a form of paternalism, but whether they are unjustifiable and vicious is uncertain. It seems consistent with, rather than contrary to, the notion of autonomy to ensure that a decision to sell one's organs is congruent with a person's own basic values, rather than tied to a special set of circumstances. The decision, for example, to sell an organ to provide for a daughter's operation or for a child's education speaks more to the need for better social support for health care and education than to the need for an organ market.

Moreover, one can distinguish autonomy in the political realm from that in the economic realm—that is, prohibiting an organ market on the grounds that the poor might be vulnerable to exploitation does not necessarily exclude such persons from membership in the political community. It seems instead ironic at best and tragic in general that a vital criterion for membership in civic life would be the freedom to dismember one's bodily self. Furthermore, an organ market would likely be structured by inequalities in knowledge, access, and power that are typical of other market systems. Thus the old governing watchword of the market is one of warn-

ing and caution, *caveat emptor*, not “all persons are created equal.”

The language of *caveat emptor* is particularly relevant to proposals for an organ market, because unlike many other commodities that one purchases, the organ sold will intimately affect the life prospects of the purchaser. The problem here is not at all like getting one bad apple out of a whole bunch or even a “lemon” from a used-car lot; an organ that is not well matched or that contains infectious agents—for example, HIV infection—can lead to an unanticipated demise. Thus, in addition to constraints on what can be sold and by whom, the autonomy argument seems open to a third kind of restriction that would regulate the quality of the organs bought and sold; indeed, it seems to *require* such a restriction because of the proviso that free choices should not harm others.

The matter of quality control is not an idle or tangential worry. Our society’s experience with a commercial system in blood transactions revealed that financial incentives can lead some persons to mask serious health factors. In particular, instances of recipients who contracted hepatitis following transfusions of purchased blood led many to conclude that a market in blood was unsafe (Thorne 1990) and that our society would be better off to move to a system based on voluntary donations, as reflected now in perennial blood drives. Less than 4 percent of the U.S. blood supply now comes from paid donors (Murray 1987), in contrast to 90 percent in the early 1970s (Titmuss 1971).

Thus the question is not whether we should have quality control and consumer protection in an organ market, but rather how such monitoring and oversight can be implemented. Obviously, an exchange of an organ for money will require third-party involvement, at the very minimum by the transplant surgeons who first retrieve and then transplant the organ and later are well compensated for their services. One important question here is whether these professionals can also provide the necessary monitoring of quality, or whether this task should be left to independent middlemen or “organ brokers” who

may bring a vendor and the buyer into contact with the transplant clinic in the first place (D. Peters 1984:40).

According to one view, independent brokers are unnecessary because transplant clinics themselves have sufficient financial incentives to ensure that the retrieved organs are healthy and will pose minimal risk and great benefit to the prospective purchaser. If a clinic becomes known for having a bad safety record, so the argument runs, it will simply lose its patrons and have to close down. Such a position would essentially leave it to the forces of the market to ensure safe procedures for the vendors and safe organs for the purchasers.

In the world we know, this seems to be a very risk-filled proposition. One needn’t look very far to find examples where product quality and safety have been compromised to enhance profit margins. Yet independent brokers do not have the medical expertise required to ensure both buyer and seller of a good and safe outcome. Moreover, brokers may be independent of institutional ties, but not of their own market interests in a profitable exchange.

The effort to ensure that interested parties in organ transplants are not double agents is already embedded in current procedures for retrieving organs. Roles are compartmentalized so that surgeons with an interest in recovering organs are not allowed to determine that a patient has died. A similar compartmentalization would seem appropriate to the question of monitoring organ quality in commercial exchanges; those who make such determinations should not have a pecuniary interest in the outcome of the exchange, or even in whether an exchange takes place. Indeed, one could argue that the involvement of an independent “organ inspector” is actually consistent with the autonomy model of ensuring that persons are free to do what they wish with their bodies, subject to the proviso that their actions (and organs) do not risk harming others.

None of these concerns—which organs can be sold, who can sell, how quality is controlled—is necessarily an insurmountable obstacle to having an organ market, or to having a limited and regulated

kind of organ market. Some proponents have expressed a willingness to limit sales of organs to those retrieved from cadavers or to provide a death benefit payment of a certain amount to families of the deceased (T. Peters 1991). These limitations would certainly alleviate the concern that a vital organ might be sold by a living vendor, or that a living vendor might not be making an autonomous and voluntary choice because of coercion or a lack of information about risks. Such a proposal would, moreover, simply underscore the significance of a quality-control mechanism. What these proposals clearly wouldn't allow for are sales by living vendors, and thus they would be open to criticisms of paternalistic intervention.

Still another alternative would expand the notion of "valuable consideration" in a market system from monetary compensation to different forms of indirect incentives. Philosopher David Peters, for example, suggests that "a market system could accommodate other forms of compensation such as free medical care, tax credits, funeral expenses, priority for family members who may need transplants in the future" (1984:40; see also Childress 1989:101). This proposal shifts the paradigm from that of "buying and selling" to something more along the lines of a barter and might, for this reason, be more acceptable to persons who find cash exchange simply too crass and degrading of the human body. Yet this system again restricts autonomy, particularly for those prospective vendors who want cash for themselves or their families in return for their organs. As well, it raises questions of justice in the allocation of scarce resources, particularly access to medical care or priority for a transplant.

While many objections to an organ market are directed at a potential lack of regulation, a regulated market, based on self-determination, can perhaps effectively counter concerns about exploitation, misrepresentation, and safety, and provide a viable alternative that respects persons' *choices* regarding the disposition of their bodies. The question is whether the autonomy rationale gives adequate respect to the *body* and the moral meaning of our embodied exis-

tence. I want to extend to the organ market an argument originally made by Paul Ramsey in the context of organ donation. Ramsey objected to the Protestant justification for organ donation rooted in *agape* and love of neighbor, with its corollary "secular transcription" of free and informed consent, because of its tendency to "fly too high above concern for the bodily integrity of the donor." Respect for choice and self-determination may be informed by a mind-body dualism that fails to acknowledge our embodied self and thereby fails to give due respect to the flesh and the body (1970:187).

The demand of moral respect for the body as the medium of revealing the self to the world is expressed in three central perspectives on embodiment. The body is a temple or sanctuary; it is endowed with a sacrality toward which the appropriate disposition is reverence rather than remuneration and awe rather than asking price. The body is also a teacher; hence, we frequently speak of the "wisdom" of the body. Bodily integrity is a condition for the experience of fullness of both joy and sorrow, health and illness. Through these embodied experiences we learn who we are and so have the capacity for compassion and presence to others. The body is finally a gift; not one of us is self-created. Embodiment therefore reminds us of our dependency on others and our accountability before an Other.

These perspectives on embodiment point to the following challenge: The autonomy argument requires us to respect the primacy of self-determination. Yet what is the nature of the self we are to respect? Should we understand the self as exclusively a chooser, a decision maker, a legislative will? If so, respect for autonomy means only respect for the choices of a disembodied mind. Should we instead understand the self as an embodied presence, a complex interweaving, however dimly understood, of reason and emotion, intellect and appetite, mind and body? If so, respect for autonomy should entail respect for the fullness of the person.

An elaboration of these models of the self would take us far afield. Two observations are sufficient for

the issue under consideration. First, an autonomy argument for an organ market not only supports dis-organ-ization of the body into component parts for sale but also dis-organ-izes the person into distinct parts of mind and body. Second, all the fundamental symbols of Christian tradition—the theology of incarnation, the ecclesiology of the body of Christ, and the soteriology of resurrection, for example—suggest that the body is intrinsic rather than incidental to self-identity and self-understanding.

Nonetheless, society already permits the selling of certain tissues of the body, whether surplus tissues like hair or oocytes, or renewable fluids like blood or sperm (though, significantly, the language of the market is characteristically not used in these contexts). In addition, control mechanisms like screening have been instituted. More generally, the provision of health care and medical services in our society is already thoroughly commercialized. Why, then, should organs be placed in a distinctive category that exempts them from exchange in a commercial market? What is morally different about selling *organs*?

Selling Organs

THE ARGUMENT FROM CURRENTLY ACCEPTED practices can of course work in both ways. We might well wish to treat transfers of all human body parts similarly and thereby question whether practices permitting the selling of some tissues should be acceptable in the first place. We might then end up prohibiting the sale of any body part or tissue rather than permitting the sale of organs as an additional concession to our cultural market ethos.

Of course, the very fact that we can label some tissues *surplus* or *renewable* suggests some dissimilarities in our thinking about body parts that could warrant differential treatment. I may feel somewhat embarrassed when someone says, “I see you got your ears lowered,” after a haircut, but I know that in due course, my hair will grow back,

and I will return to the vitality of my former looks. I learned from the wounds and injuries of childhood that my body has a remarkable capability to restore itself to full vigor following some loss of blood and, from the traumas and indulgences of adolescence, about the body’s own means of renewing sperm. The initial confusion and fear accompanying menarche for females gradually become incorporated into a familiar, if uncomfortable, cycle of loss and restoration.

The visual experience of these tissues and fluids, including the experience of their *temporary* loss, may suggest to us that they are not integral to our sense of self and even capacity for life. Clearly, their permanent loss is quite another matter. We are, for example, familiar with the stories of males who undergo a more challenging diminution of self-esteem upon loss of hair or virility, or the reinterpretation of self undergone by women during the experience of menopause. Blood historically has been a central symbol of human life and of the life-giving force, surely because a person can withstand the loss only of a certain quantity of blood before becoming physiologically compromised. Yet as suggested by the experience of receiving a transfusion, I can do just as well with someone else’s blood as I can with my own. I require blood to live, but not *my* blood.

By contrast, the organs—heart, kidneys, liver, pancreas—as well as even some regenerating tissue, such as bone marrow, are veiled from our view. They may therefore seem more integral to the identity and mystery of the self. Clearly, this is so with the heart, which for centuries was considered the seat of the soul and only recently has been displaced as science has revealed more to us about the brain. Yet this sense of identification of an organ with the self can pertain to other organs, as suggested in the psychological transference that occurs with organ transplants, where family members who have donated an organ will often refer to their deceased relative as “living on” in the body of the recipient.

This kind of language is not, ethicist William F. May has argued, theologically problematic. It may be interpreted as a sentimental aspiration for “sym-

bolic immortality," perhaps particularly necessary in a scientifically oriented culture that buries eschatological hope along with the corpse. By May's account, the Christian can discern images of God's self-donative love in an organ donation that mortal beings, nonetheless, cannot reproduce (1991:190, 191). Such language may likewise express a family's desire for ongoing relationship with the deceased or a profoundly human need to find redemption in what, in many instances of organ transplantation, are tragic circumstances, both of which signify a deeply religious quest for purpose and meaning.

Whatever meaning is attributed to such language, its use is almost exclusive to the context of organ donation. It is virtually absent from the use of hair, sperm, or oocytes by others, and only rarely appears in the case of blood transfusions. Visibility and veiling of the body does make a symbolic and moral difference.

This hiddenness is also connected to matters of accessibility and risk. If my hair is greatly desired for purposes of making a wig, it can be had at minimal inconvenience to myself, perhaps 15 minutes of time, and at no risk, unless the person cutting is sloppy with the scissors. Sperm may be retrieved not only without risk but with some pleasure. Access to blood does require an invasive procedure, something we as children learned at the hands of nurses. But a needle prick is fairly infinitesimal as far as risks go, and besides, it always seems connected with rewards, whether a lollipop from the nurse or the good feeling that comes with participating in a blood drive. The invasiveness can be more substantial with oocyte retrieval, although newly developed nonsurgical methods that rely on ultrasound, thereby enhancing visibility, have facilitated accessibility and significantly reduced risk.

By contrast, the organs or bone marrow so much in demand are accessible only through more extensive invasive procedures, and they require trained specialists, such as surgeons. They also involve different degrees of risk, depending on the organ or tissue involved and on whether the donor is alive or

dead, though both kidney and bone-marrow transplants from living persons are still considered low-risk procedures. Nevertheless, a level of disorganization to the body is evident in such procedures that isn't obviously present in the cases of hair, sperm, blood, or oocytes.

We know as well that the surplus and renewable body parts are obtained for quite different purposes than the vital, solid organs, and our reluctance to engage in commercial exchange may well increase as the purpose is deemed more central to *living* than to *living well*. Hair used in a wig satisfies an aesthetic desire of another person, but it is not a necessity for living. Sperm and eggs are necessary to the creation of new life, but those new lives themselves are not clearly necessary. At the least, it continues to be an arguable point whether having a child falls in the realm of human aspiration and desire or of basic human need. In contrast, blood comes the closest to serving the purposes of organ retrieval, since it provides the necessary means to sustain the lives of present persons. This proximity in purpose may explain why the blood-procurement system has been almost entirely transformed into a voluntary-donor model. It does seem, however, that a close connection exists between the seriousness of the need and our (un)willingness to allow a system of commercial exchange to meet that need, as suggested by Emanuel Thorne's observation: "In cases of life and death . . . markets are often not allowed to operate, for ordinary market allocations demonstrate too clearly that life is not priceless, and that some lives are more valuable than others" (1990:42).

The distinction between surplus or renewable body parts and vital ones, then, pertains not only to the capacity for maintaining biological life but also to a relation between the part in question and our sense of self-identity. We are more than our bodies, and yet we know ourselves only through bodily existence and life. The fact that the solid organs are hidden from us, and serve more essential purposes, may well reinforce this sense of a vital connection between organ and self, even if we, unlike generations past, now know full well that we can live with

only one kidney or with someone else's liver, heart, or pancreas.

Such points may help explain why, to use Kinsley's language, we experience "horror" and "revulsion" regarding the selling of organs, while tolerating and encouraging the selling of some other tissues or fluids. In short, the idea of an organ market seems to reflect or transform the human body into a commodity or property in a manner not present with surplus and renewable tissues. We are not worried simply about selling an organ, but because symbolically these organs help define in a vital way who we are, we are also concerned about selling ourselves.

We can, moreover, understand the concern about commodification of the body to reflect the profound centrality of embodiment to our personal being. We do not live as a solitary mind or an autonomous will, which is in some kind of dualistic relation to a burdensome body, but rather as embodied selves—persons who live, learn, and act through the body. Moreover, the needs of others, be they for food or shelter, or for something like an organ, are mediated to us precisely through our embodiment. In a fundamental way, then, a proposal for an organ market seems to suggest severing the body from our sense of self and personal identity. The body becomes incidental rather than integral to who we are and, just as significantly, what we can be for others.

Sales and Gifts

I HAVE TRIED TO SUGGEST A RATIONALE for treating solid organs differently from surplus or renewable fluids and tissues: the former simply seem more central to our sense of self. To sell an organ symbolizes a selling of part of the self. Yet how is this different from the kinds of severing that occur under a model of voluntary donation? Indeed, if one's organs are so integrally related to self-identity as suggested above, one might wonder that any organs are donated at all.

Such sentiments, one suspects, are part of the reason our society finds it preferable to retrieve organs from cadavers, where the identity of the self with the body has undergone its own form of natural severing. Yet this seems an inadequate response, in part because it misses the sense of binding and connectedness we experience with others through *gifts*. Organ transplantation in particular is a paradigm of the *gift of life* in human relationships, within which are embedded deeply religious and transcendent themes of sacrifice, communion, and love (Parsons, Fox, and Lidz 1972:412). The case for organ donations rather than organ sales seems significantly influenced by the moral meanings we attribute to gifts and gift relationships.

We know from ordinary relationships that a gift that is handmade, such as a quilt, a scarf, or a jar of preserves, is typically experienced as more meaningful for both giver and receiver than the identical item purchased as a commodity from a store. This occurs in part because the identity of the giver is symbolically bound up with the gift. A powerful phenomenon of personalization attends practices of gift giving, in which the gift is transformed into an extension of the giver's person and individuality. As Marcel Mauss, in his classic anthropological study *The Gift*, puts it: "to make a gift of something to someone is to make a present of some part of oneself" (1990:12). Thus the moral meaning of a transfer of a body part or tissue can be entirely different depending on whether it is understood as a gift or as a commodity for sale—that is, as something that has been "alienated" from the self and thereby is alien to the self.

The self-expressive character of gifts also suggests that central to the notion of gift is the creation of community. The self through the gift extends an invitation of relationship to the recipient. The sharing of self—physically, emotionally, spiritually—displays a profound sense in which the fullness of who we are as persons is realized only in and through relationships with others. The contrast with the autonomous self of the market ethos, whose relations

are restricted to minimalistic contracts, could not be more marked.

Thus the moral status of the recipient is reconceived in a gift relationship. The offering of a gift not only conveys an identity about the self but also informs the self-understanding of the recipient. One indication of this is the prominence of themes of reciprocity and responsiveness in gift practices. Moreover, as theologian Paul Camenisch insightfully suggests, the meaning of the gift for the recipient may involve an empowering, expansive experience: "Good giving . . . enables the recipient also to become a giver by demonstrating the goodness of gifts and of gift relations . . . and by enhancing rather than undercutting the recipient's sense of self-worth so that the recipient can envision himself as giver too, as one having something worth giving" (1981:29).

The theme of self-giving for purposes of creating relationships and liberating the other is of course at the moral heart of the formative religious traditions of our culture. It is the basis of the covenantal communities, actual and idealized, portrayed in the Jewish and Christian Scriptures; and in Christianity, its culmination is the self-offering of Jesus of Nazareth. That offering is a gift of life—new life and eternal life—that dissolves a sense of estrangement from self and others in a new community, the body of Christ. That community commemorates this gift in the focal liturgical rite of communion. This foundational act of sharing of self, as May suggests, is a distinctive and positive reason for donating one's body as a gift to others: "Believers may participate . . . by their readiness to share a portion of their bodies and blood with others" (1991:190).

It may of course be asked what relevance this brief portrayal of the moral significance of gifts has for current practices of organ transplantation. Indeed, current policies have gone to striking lengths to render these gifts of life impersonal and faceless. The urgency of medical need and the impersonal mechanisms of procurement and distribution, such as donor anonymity or the partitioning of medical teams into attending physicians who declare death

and surgeons who retrieve or transplant the organ, work to preclude relationality and responsiveness. The personalization of the gift by the donor seems blocked by impersonal procedures, and the recipient will in almost all cases (excepting living, related donors) find it virtually impossible to identify the gift with a particular person. In short, the "gift" language of organ transplantation may provide appealing rhetoric rather than moral substance.

Morally valid concerns support the impersonalized constraints on gifts. In large measure, these concerns revolve around what Parsons, Fox, and Lidz refer to as the possible "tyranny" of gift relations (1972:414). A prospective donor or family confronted with the immediate and vital need of an identified person, rather than that of a statistical stranger, will likely experience a controlling compulsion to donate. The sharing of self may well be vitiated by a subtle but undeniable coercive element when an unrelated stranger is given a face and identity. In this context of life or death hanging in the balance, the moral integrity of the giver, and thus his or her expression of self-identity, may be enhanced by impersonal procedures.

The gift to the statistical stranger, moreover, can affirm a much broader realm of relationships and express a social self-understanding. As Thomas Murray has argued, "Gifts to strangers affirm the solidarity of the community over and above the depersonalizing, alienating forces of mass society and market relations" (1987:35). Impersonalized procedures should not, then, be equated with the depersonalizing attributes of a market ethos, nor should an imperfect approximation of a gift relationship in organ transplantation be taken as an argument for the necessity of a market system. A context of giving and receiving (as compared with buying and selling) can transform the threat to the identity and integrity of the self into a profound affirmation of community and interdependence.

The ethos of gift giving thus offers more social space for the flourishing of trust in relationships with others. The ethical concern with the marketplace in general, and in an organ market in

particular, is that it seems to presuppose distrust rather than trust as the basis of human relationships. We express suspicion that persons will be manipulated and exploited, that vendors will not be fully informed about their alternatives and the risks of the procedures, that buyers may be placed at risk because the profit incentive compromised safety standards, and so on. The gift model expresses a richer account of human beings and human relationships than is possible in the "moral logic of capitalism" or in an ethic that relies on *caveat emptor*. We know our lives have more meaning than trying to avoid harming and being harmed, and the gift model of organ donation reflects our genuine interests in aiding those in great need. The sharing of body parts

witnesses profoundly to our capacity for a sharing of self and to shared humanity.

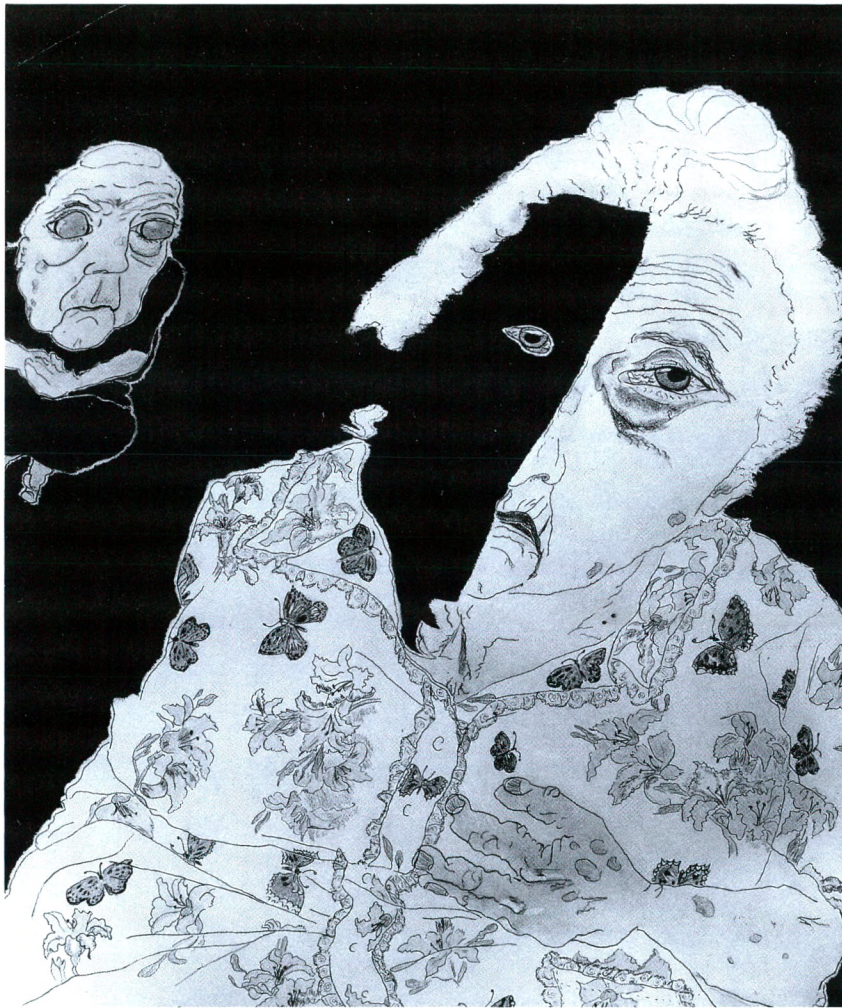
An organ market, with necessary regulations and constraints, may be an ethically acceptable method of organ procurement, but I do not view it as ethically preferable to the gift model of organ donation or even as a desirable approach, and I seriously doubt that it will resolve the shortage of organs. Whatever the outcome of forthcoming policy debates, the question at stake does not simply concern social utility or the boundaries of state intervention in private choices. We are equally articulating fundamental and profound views of ourselves and our bodies and of what we can be for others. ☉

NOTE

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Stroke. Crayon and colored pencil by Elizabeth Layton, 1978.

*Tenth in a series edited by Steven H. Miles
and Kathryn Montgomery Hunter*

The Case Voices

Tod S. Chambers

TYPICALLY MEDICAL ETHICISTS WRITE CASES IN the third person, concealing how they learned about the case and reporting indirectly the values and opinions of the participants in the drama. This style of case presentation persuades the reader that all the essential information has been included and no relevant facts omitted, yet the various perspectives of the participants are often lost.

I first heard of Martin Lubell's* story during an ethics conference for third-year medical students in a Boston hospital. Later, when I met the attending physician in psychiatry, I casually mentioned the case and was surprised to hear a quite different version of the story. In the following case presentation I offer edited transcriptions of conversations with some of the participants in the care of Mr. Lubell. I didn't "interview" them; instead I sat down

with each and asked simply, "Tell me the story of your relationship with Mr. Lubell." I allowed their memories to guide what they thought was essential in responding to my request. Each participant knew—as I turned on the tape recorder—that I would use his or her "story" as part of a chorus of recollections. None of the medical team had an opportunity to review Mr. Lubell's chart before speaking with me, and thus the facts in each telling differ slightly. I edited these narrations where I thought the information presented was redundant and where there was general agreement concerning the events. It is not my intention to create a "master narrative" by bringing these voices together; I hope that this presentational form merely thwarts any attempt to disconnect "facts" from particular tellers. I am aware that other voices could be included, and should be, if we wished an even thicker rendering of Martin Lubell's predicament. As I gathered these stories, many participants concluded by saying, "You should speak with that person if you really want to understand what was going on," and I found myself asking, as I moved from one person to the next, "How many voices are needed to make a 'judgment'?"

**The names of all participants in this case have been changed.*

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Alexandra Rouel, Resident

I FIRST HEARD ABOUT MR. LUBELL while I was on call in mid-July. A rehab resident called just shortly after five and wanted to do an emergency transfer to psychiatry. From the discussion on the phone I sensed that this was a very stressed-out resident who was overwhelmed by the patient and was trying hard to get rid of this guy ASAP. It was not possible to work out a transfer at that point, so I instructed him in the use of neuroleptics to help the gentleman calm down enough so that they could keep him and everyone else safe. Earlier that day, apparently, he had thrown himself on the floor and had been acting very inappropriately because he did not want to do what they wanted him to do, or, better put, he didn't want to follow the recommendations. Sometime the next day the transfer was effected, and I was assigned his case.

David Ruben, Attending Physician

MR. LUBELL CAME TO THE PSYCHIATRIC inpatient ward as an emergency transfer patient from the rehab unit. Prior to this, I had never seen him or had any contact with him. He had been taken care of there by another psychiatrist whom he had "fired." And this man had been working with him for five or six months. Basically, Mr. Lubell was very depressed. He was in his late sixties, and he had had a stroke—in January, I believe—that left him progressively unable to talk. He had had, in a sense, a personality change with this problem. There probably were signs of evolving and continuing stroke—not to the degree that he had when he was paralyzed and speechless—but his speech was worsening. Very early in his admission I called his wife, and the message on the answering machine was still Mr. Lubell's from probably two or three months before. At that time his speech was still quite intelligible, so the loss had progressed very rapidly. You had some sense of how devastating this experience really was for him because he was a very bright, very verbal guy who studied a great deal. In his own way he was a scholar, even though his work was not particularly scholarly. He prided himself on his scholarly study.

He was transferred because he had bitten a rehab unit staff member and had made a suicide attempt—such as he could—by trying to hang himself. He was adamant that he was going to take his life. When he came to our unit, he was very, very angry and would threaten anybody who came in the room. He would hit them or bite them or do anything he could to hurt them. He was also very angry with his wife, who presented herself as surprised at the degree of his upset. He didn't want to take medicine, and he really didn't want to have anything to do with the resident. Both the resident and the medical student were women; that seemed to be a part of the difficulty.

Alexandra Rouel, Resident

WHEN I FIRST MET MR. LUBELL, I had already heard quite a bit about him. Multiple strokes had left him unable to communicate verbally. He had little use of his left hand, and although he could walk, that was difficult for him, and the difficulty had been exacerbated by a knee injury sustained in a car accident two years earlier. He came with notes indicating that he had fired his rehab doctor and lost control of his behavior several times while in rehab. When Dr. Ruben assigned me to the case, I already thought that we might be dealing with a depression—someone post-stroke has a high chance of having a depression. Certainly his circumstances were extremely frustrating. I learned that he was a very intelligent man who operated at a sophisticated level. He was a scholar of ancient history and took great delight in having intelligent conversations with people, interacting in an intelligent fashion, and now he could not do any of that. So the loss was tremendous, besides the loss of his independence, which was, of course, massive in its impact. All these losses suggested the possibility of a depression. Because the man had had several neurologic assaults, it was also possible that he was having the behavioral problems simply because the parts of his brain that normally allowed him to control aggressive behavior just weren't working anymore.

When I first went into his room to talk to him, he was sitting in a chair. I remember walking in and sitting down. There wasn't really anywhere to sit. He was in a chair and it's inappropriate for me to stand up and talk down, so the only place I could perch was on the edge of the bed. So I perched on the edge of his bed and introduced myself while he reached for his pad of paper. Very slowly and laboriously he pulled it to his lap, struggled for a pen, got hold of that, needed assistance aligning the pen in his hands, and then he struggled to write two words. It took him about five minutes to finish—he had written "Nice legs." I was somewhat taken aback by this, and I said to him, "Here you are. You're in the hospital. You've had a couple of strokes. You can hardly walk, you can't talk, and you've lost the use of one of your hands. When I ask you how you are, the first thing you say to me is 'Nice legs'? What is this about?" And he laughed and laughed and seemed to be, in spite of all that had happened, a pleasant man, but a man who had a lot of difficulty doing what was important to him.

Through the course of my interaction with him I came to feel there were three Martin Lubells. Number one was a very successful, intelligent man who had long conversations with his wife, was the master of the family, managed all the finances pretty much himself, ran the household in a sense, and was the primary nurturer to his children. They called me multiple times while he was in the hospital and clearly cared very, very deeply about their father. The second Martin Lubell was the man I met that first day. This was a man who was trying to keep his spirits up, could be jovial, wanted people to like him, and was still, in spite of his tremendous handicaps, able to evoke in other people the feeling that this is a nice guy. As the days wore on, I met the third Martin Lubell.

Cathy Smith, Social Worker

MY ROLE ON THE UNIT is to do an initial assessment based on the data in the patient's record, to interview the patient, and also to make contact with the family. Mr. Lubell was receptive to being inter-

viewed. It was hard to interview him for any length of time, not because he was uncooperative but because of his difficulty in communicating. He had the condition of dysarthria, which made it very difficult for him to enunciate in a way that could be understood—he kind of grunted and groaned. You could see him grow very frustrated as he tried to communicate with you. His word processor was eventually brought over, and that helped him communicate much better, but it was real labor because he had to peck out one letter at a time. He tried to write with a pen, but that was really difficult to read, so he would get frustrated with that too. But he tried very hard to communicate, and eventually we were able to communicate very well through the word processor.

David Ruben, Attending Physician

WE WORKED WITH HIM and worked with Mrs. Lubell, trying to figure out how all this came about, and the only thing we could put together was that probably the relationship between them had been very tense for a long time. He had been kind of pushy with her, but in a very nice way—not in a man-who-abuses-his-wife kind of way. She was the sort of person who did whatever she was told to do. She certainly was a very bright woman, quite accomplished as a sculptor, an art teacher, and so forth, but that relationship was a stratified arrangement. With his disability, it seemed not only that their roles had changed but that her manner with him had changed. She had become quite harsh with him, and he couldn't believe it! This was how we understood it.

Alexandra Rouel, Resident

WHEN I FIRST CAME INTO THE SITUATION, I got the impression very quickly that the sons and the daughter felt hostile toward the mother, that they thought if she would just get her act together and become a nurturer, everything would be fine. The problem was that Mrs. Lubell isn't that kind of person—she's a very nice lady but very talented, very intelligent herself, an artist in her own right. She

doesn't seem the kind of mother who baked cookies or put bandages on the "boo boos." Whatever it was she didn't do, something about Mrs. Lubell made her children feel that she wasn't as nurturing as their father. And her children resented this enormously. They also resented the fact that she had expressed feeling incapable of carrying on with the burden of Mr. Lubell's care. This was hard for them to accept. It was hard for her to say, and she was in tears when she talked about it. Initially I wondered where Mrs. Lubell stood in all of this because when Mr. Lubell first came, he was pleasant, he was jovial. I thought, "What a nice guy. He has these physical challenges, but he's a nice guy. Why doesn't she want to take him home and take care of him?"

As time went on, Mrs. Lubell was able to tell me more about what she was experiencing, and I learned that this was a woman who was realistic about what she could and couldn't do. She felt very guilty about not being able to meet the needs of her husband. She loved him dearly. She felt guilty that she couldn't meet her children's expectations, but she was very aware that if she had to continue as before with Mr. Lubell at home, her own health was going to suffer. She also feared for her own safety because he had struck out at her on at least one occasion.

Cathy Smith, Social Worker

HIS WIFE IN MY FIRST CONTACT with her was needing to talk to someone about all the things that had happened—she had a very profound sense of loss and frustration and sadness about it all. She, and then later the sons and daughter, described Mr. Lubell as having always been an extremely com-

petent man, the person who looked after his family. He was a very good provider, he took a lot of pride in controlling things, and his wife and his children had always looked up to him as being someone who could master any problem that was put before them.

So to see him in this condition—changed from someone who had been extremely competent and very independent to someone who was now very impaired and needing a lot of help and so angry—was really hard on them. Mrs. Lubell also had a sense of loss about the dream for their retirement, about what they had imagined their older life together would be like. Clearly that couldn't be the same now. She had a lot of financial worries. He needed so much care—how was that going to leave her? She was very anxious about being left penniless. I think they did have assets and were pretty stable financially, but

she was in a panic about what the future would hold. She was also very angry with him over his difficulty controlling his temper. I think he had sworn at her. He had hit her. He had on several occasions threatened to divorce her. Mrs. Lubell was also really panicked about having to take over responsibility for doing a lot of the things Mr. Lubell had done. He handled the finances. He took care of business. He knew all about the money. The way she put it, she didn't know about anything. She didn't know how much they had in savings. She didn't even know how to balance a checkbook. Not for lack of competence because she was a very competent lady herself. She was a sculptor and taught art at a local university. So her whole life was her art and her teaching. You got the picture that this couple—though they were described as having a very compatible marriage—had some distance between them, that he had his job

Mr. Lubell maintained that there was nothing the matter with him, that there was no reason at all he couldn't go home, and that there was no reason for him to take medication or be treated in any way.

*—David Ruben,
Attending Physician*

and his life and his things, and she had hers. Everyone relied on him to take care of business, and now he was just a shell of the man he used to be. So the big dilemma was what next for Mr. Lubell? Where would he go from here?

When I was with them, her inability to tolerate his impairment was really quite notable. She would take big deep sighs. She would roll her eyes. She would fold her arms across her chest and shake her head and say—in a very loud voice, within earshot of him—“Do you see what I have to put up with? Can you see this? This is what I am going to have to deal with now when I get home.” Then later she would feel very guilty for having had this kind of response to him, but she was beside herself in how to deal with all this. It was really sad: the two of them would be in a room together, and she would try for a little while really hard. It became more apparent that to have him go back home with her—just the combination of all the things I described—was probably not the best situation for either of them. At that point we began to talk to Mr. Lubell and the family about nursing home placement.

Alexandra Rouel, Resident

THERE WAS A MEETING AT ONE POINT. The social worker, one of the nurses, and I sat down and talked with Mrs. Lubell about possible options. After I learned how difficult it was for her at home, how small their apartment was, and what stress it would place on them both to have a third person in the house around the clock, it was my feeling that he really would have a hard time at home. Even though he appeared to be behaviorally more in control of himself, I did not have much confidence that he would be able to maintain that at home. He was also impulsive—that’s part of the disorder. He would fire people, and he had done that previously. I had an image of him going home and firing the day-care person, and that would leave just Mrs. Lubell. Mrs. Lubell is a tiny woman, and I knew that if he fell, he’d be right back in the hospital. I didn’t want to let that happen. This was a case where you really had to think about the family system: there were Mr. and

Mrs. Lubell, and their children off in other states. The sons and daughter were influencing what was going on here, but they weren’t living the day-to-day reality, so it was hard for them to understand. It was very complex.

So we sat down with Mrs. Lubell, and we said this is what we perceive the options are, and our recommendation is a nursing home. She knew very well what his response would be. She knew that he would not want to go—that it would be very upsetting to him. She said she would talk to her children. The children were all upset. I can’t even tell you how much time we spent on the phone. We talked and talked and talked. They had a hard time understanding, but eventually they came to understand. Their mother was able to express her true feelings about this and how hard it was for her. We were able to assist so that the children were better able to empathize with their mother.

David Ruben, Attending Physician

MR. LUBELL MAINTAINED that there was nothing the matter with him, that there was no reason at all he couldn’t go home, and that there was no reason for him to take medication or be treated in any way. It was a standoff. Mrs. Lubell was taking the position that she wanted nothing to do with him, that he was impossible. He was threatening her; every time she came he was very nasty to her and threw her out. He needed a terrific amount of attention in terms of toilet, he couldn’t walk by himself, but he was saying that he didn’t need help from anybody. He just needed to go home and have his wife take care of him.

Alexandra Rouel, Resident

AS THE EVALUATION CONTINUED and we tried various medications on Mr. Lubell, he seemed to become more calm, better organized, and a bit more able to deal with things that were stressful. But as time went on, we realized that we couldn’t keep him in the hospital forever. In some ways I think he would have been happy to stay there—he had round-the-clock nursing care, and this is what he wanted.

But this sort of care was going to be very difficult for the family to manage in their home, both financially and physically.

David Ruben, Attending Physician

I TALKED TO THE FAMILY ON THE PHONE—one son in New York and the other son and daughter in Seattle. They were just angry. They felt that this was an impossible burden on them, and they had various things going on. But we did encourage them to come in for a meeting.

It was a very unhappy experience for most of the people. The staff were very afraid of several of the people there. The son for some reason looked like he was going to be striking out. We included Mr. Lubell in the meeting, and this was what the family found so irritating and betraying. But it was our intention to make this a meeting in which every person who had a voice was in the room rather than getting the family together and figuring out a strategy for how to deal with Mr. Lubell.

Alexandra Rouel, Resident

AT THE FAMILY MEETING we once again presented our recommendations about placing Mr. Lubell in a nursing home, and he was very angry. The one word he could say clearly was “No.” That room felt like an inferno to me, with the three siblings and Mrs. Lubell; everyone was trying to talk to Mr. Lubell, and he was trying to do his thing with his pad and pen. We started the meeting by asking him to be quiet and just hear us out. This was very frustrating to him, and there came a point where it was all at a stalemate. Dr. Ruben was really impressive. “Well, it’s clear that you all have things to talk about here, and we’re going to let you make your decision.” So we all marched out. For the next hour you could hear them through the whole first floor, screaming and yelling, “No! . . . No! . . . No!” “But Daddy!” “No!” It was just incredible.

Cathy Smith, Social Worker

THE FAMILY MEETING WAS A DISASTER. The daughter was herself on the verge of hysteria—

jumping out of her chair, crying, running across the room to him, down on her knees, pleading, grabbing him by the hand. “Oh Daddy, please,” they’re begging him. “We don’t want to do this to you, but this is the thing that has to be done.” And then he would write a note or grumble out in a way that someone could recognize, “You are no longer my family. You’re dead.” In Judaism, the ultimate cut-off from the family is “You’re dead. You’re not my family any more.” So he was saying incredibly provocative things, and the family felt bad enough, and now he was saying, “You’re no longer my family. You’re dead. I want a divorce from you, Barbara.” Rather than having it be an opportunity for the family to try to offer him some support, the meeting turned into a big moment of heartbreak. Everyone was crying, and we didn’t seem to be getting anywhere. But the one thing it did show was that Mr. Lubell, despite all the attempts to reason with him, was a very controlling, very stubborn man, which fit with the description of how he had been all his life. What else could we do?

David Ruben, Attending Physician

WE TALKED WITH THEM about a guardianship—it would have been a sort of adverse guardianship because he would have fought it—to make sure that he got cared for. I don’t think I did a good job because I don’t think I was understood or heard. It needed to be said, but maybe there was a better way to have said it. From my point of view the issues had to do with certain realities: there had been suicide attempts and physical endangering and certain mental endangering, and all that had an impact on all the people. We said that a certain decision had to be made in a certain reasonable amount of time. The goal was to prevent making the hospital his home so that people didn’t have to deal with the issue.

Cathy Smith, Social Worker

THE NEXT QUESTION THAT CAME UP WAS, Is he competent to make this decision on his own behalf? And this raises the question of a guardianship. I’ve been involved with a lot of guardianship cases but

never one where it hasn't been perfectly clear to me that the person wasn't competent. With Mr. Lubell I wasn't sure. I thought, gosh, he's got impairments and he's got a lot of problems, but whether he's incompetent—ultimately that's the judge's decision. My own instinct was that we probably weren't going to be able to prove it successfully in court. We left it up to the family at that point.

Alexandra Rouel, Resident

I WAS NEVER REALLY ABLE TO WORK with Mr. Lubell on what I perceived as the principal issue: how to help him accept the fact that he had been seriously damaged, help him work through the denial of this, and help him start preparing psychologically for a very radical change in his life to 24-hour nursing care. It was very frustrating for me not to be able to do that work. Part of my conflict was trying to help this person maintain his personal dignity, his right of self-determination in the face of such devastating impairment, when the neurologic consequences of the stroke or maybe the psychological consequences of this man's personality were not allowing me to do the preparatory work for the next step. And what do you do when you've got a patient who literally takes an hour to answer when you say, "How are you today?" and you have a lot of other patients simultaneously whose needs are different but no less important?

David Ruben, Attending Physician

ABOUT A WEEK AFTER THAT, Mr. Lubell fell, which was not unusual. He'd been started on some anti-Parkinson's medicine by Dr. Fiedor, a neurologist, because it was thought that maybe Parkinson's disease was adding to his difficulty. The next day I was making rounds, and I saw Mrs. Lubell there, along with Dr. Fiedor. There had been a minor disagreement between myself and Dr. Fiedor about that medication because it can sometimes make a person more agitated. We were the prescribing people, so we had started him on some very low doses, but Dr. Fiedor wanted to give higher doses, which he eventually did. After he had examined Mr.

Lubell and talked to him, he said, "I think that I would like to transfer him to my service because I think that I can maybe help with this problem." He was also saying that Mr. Lubell should not go to a nursing home and that he was going to rescue him. He did take Mr. Lubell, and I offered to be involved if he wanted me to be. He said no, he thought he could deal with this. In fact, he was leaving town soon after, so it really fell upon Dr. Ashe, his associate, to take care of Mr. Lubell, and then he was discharged home to Mrs. Lubell.

Alexandra Rouel, Resident

THE NEXT THING I KNEW, he was gone! I left for the weekend and came back to learn that apparently he had presented his story to Dr. Fiedor, and Dr. Fiedor had decided to transfer him and make him well. My sense was that the system had been very successfully co-opted and that by transferring him to neurology we were offering the family as a whole the opportunity to avoid dealing with a reality that some of the family were sometimes acknowledging and others not. Who wouldn't want to deny this reality?

Cathy Smith, Social Worker

I CAME BACK TO WORK on a Monday, and Mr. Lubell was gone. He was gone. He just left.

Raul Fiedor, Attending Physician

I HAD SEEN MR. LUBELL on a couple of occasions as an outpatient when he reported to us an increasing number of falls without increasing weakness. Because of the reported falls it was clear that he needed additional help, which was provided in the rehab unit. Over the ensuing months Mr. Lubell's situation was apparently difficult to control at home, and I learned that he had been hospitalized under the care of psychiatry. I then saw him as an inpatient.

He was not very happy about being hospitalized under the care of psychiatrists because he never felt that he had a psychiatric problem. My impression was that a primary neurologic problem led to his falls, and his progressive motor disability and difficulty with communication led him to tremendous

frustration in his dealings with other people. Every time I met him I thought that he was polite, very charming, always willing to express his problems and his viewpoint—he had to do that with a computer because of his difficulty with verbal communication. Much of what he wrote made sense to me. I never felt that he was out of touch with reality. He never felt that he was crazy, that he needed psychiatric care. I tried to convey to him that being under the care of psychiatry didn't mean that he had a psychiatric problem per se or that he was crazy. On one occasion I requested his transfer to neurology so that I could give him some medication, not because I ever felt he had Parkinson's but to see if we could improve some of his mental disabilities. We didn't achieve the improvement that we expected, but he was clear that he felt at ease in a neurology ward, not in a psychiatry ward. We exchanged books. He gave me a book as a present; I gave him a book as a present, a book about maps and history. I always had a great appreciation for him. I think that I was able to understand the man because although he certainly had great difficulties in conveying his thoughts verbally, he unquestionably had a superior intellect. There was no question that Martin had become an unhappy man, a very frustrated man. I think he had a very dear and loving wife who was overwhelmed by his deterioration and the fact that we were unable to provide him with a cure or a treatment that could halt his progressive disability.

David Ruben, Attending Physician

THREE WEEKS LATER I got a call from the woman who was taking care of Mr. Lubell at home. She said, "This is a terrible situation. He's hitting me. He's hitting his wife. He is being very abusive to her. She is at the end of her rope. What do I do?" I said, "Call Dr. Fiedor because I don't know what's going on and I'm not really involved in it. If you have a psychiatric emergency or a problem you can't address, bring him to the emergency room. There isn't anything I can do over the telephone." Apparently that happened. They weren't able to reach Dr. Fiedor, so they brought him to the emergency room. I heard from

the staff that this guy was really angry and was fighting people. Eventually they did get Dr. Fiedor to come down. Dr. Fiedor called me from the emergency room and asked me to admit him into psychiatry because this was not a situation he could deal with. I said I would certainly be glad to do that.

We didn't have any beds on the older adult unit, so I admitted him as an emergency to one of the general psychiatry units with the intention of transferring him. Well, Mr. Lubell was not willing to sign in, so a resident saw him and they signed a hold on him, an involuntary hospitalization, because in their assessment he was out of control. About eight o'clock that night, he was really angry. The anger was certainly understandable for anybody who was brought to the hospital when he didn't want to go and was hospitalized, against his will, in the psychiatric unit. His intensity and threateningness were still very much there, so I actually signed the second certificate—I felt it was appropriate for him to be there.

Alexandra Rouel, Resident

AS I UNDERSTAND IT, one of the first things he said was that he didn't want me as his doctor.

Cathy Smith, Social Worker

AS YOU CAN IMAGINE, by this time Mrs. Lubell was beside herself; she felt that she had been put through a knothole. She was exhausted, inconsolable, very irritable, and very angry, but she felt, "I gave it a try. I did the best I could. My conscience is clear. Nursing home is the thing to do." The family supported her on that.

Pablo Lopez, Resident

I THINK THE SECOND ADMISSION was better than the first for him because he was in a very overprotective environment. He was a victim of his stroke, and everybody was really pressuring him, and it was a vicious circle he couldn't break. This man's thinking was very lucid; he was highly intelligent, very motivated, a workaholic, a good businessman. I

know that because I come from a background of businesspeople.

At first he didn't want to engage me much. He had a very close relationship with a neurologist, Dr. Fiedor. It seems that Dr. Fiedor has this Latin American flavor. I am from South America originally, and I know that physicians there are very close to their patients. They touch the patient, they are like friends—it's part of the culture. Of course in psychiatry you have to maintain a certain distance, apart from the normal distance in American culture. It is a different way. He and Dr. Fiedor were very close, and this man said, "I don't want Dr. Ruben, I want Dr. Fiedor." He couldn't understand at first what kind of help psychiatry would offer him. During the two weeks he got better, he was typing clearer sentences in the computer. I met with his son and also with his wife—they had spent many, many years in marriage, maybe 40 years. Very nice woman, very intellectual. She was an art teacher, a professor, a lot of culture in the family. It was a very sad situation. I tried to work as hard as I could with this man because he was really worth working with. I had this feeling that he wanted to be helped. At first he was denying his illness, his stroke, and then he started to accept it.

Saman Pezeshki, Third-Year Medical Student

WHEN I FIRST WENT TO MEET MR. LUBELL, the room was dark, and I saw an older-appearing man slouched over in his wheelchair with the headphones of a Walkman in his ear. His head was bent to the side, and he was kind of broken-looking; he was just staring at his computer or looking outside the windows. I went up to him and introduced myself and said I was there to interview him and ask him some questions. He looked at me silently, maybe untrusting. He started going toward his computer, and we got to meet that way. I don't remember exactly what we talked about; we just sat and chatted. I asked him some questions about what had happened, but he didn't get to specific points. He would talk about other things—it was very frustrating. He would print wrong letters, and he would often go back to

erase. Even when I understood what he was saying, he was very determined to print the right thing. So he would type it and then look at the screen, and when he saw a wrong word, he would go back and erase. Even when I said, "Oh, I understand, don't bother," he wanted to prove to me that he could write. Perhaps it was because people were impatient with him—that's the impression I had. He wanted people to sit there and talk to him. After the first time I realized that, so I went in with the expectation that I was going to be there for a while.

I went in every day and talked to him, and it took a long time compared to other patients—an hour, an hour and a half. I went two or three times a day, and I noticed that after a while he started opening up to me. It seemed as though he would tell me more than other people, perhaps because I didn't want to focus on his disease as much because I didn't have the responsibilities that the resident and Dr. Ruben had. So we just talked about anything. I realized how aware he was. When I first met him, he didn't seem so aware. As time went on, I realized that this man had normal feelings like everyone else but unfortunately couldn't express them or people were impatient with him. It made me want to try to figure him out. It was actually interesting for me to spend the time with him. One of the issues that came up was that he was not happy with what was being done there.

For some reason this patient had a bond with Dr. Fiedor, though Dr. Fiedor in my opinion was not very involved with the situation. He wasn't really involved, but he was nice to him, and Mr. Lubell saw him as someone he could trust. Perhaps Dr. Fiedor did not tell him his opinion as strongly as Dr. Ruben did. The first time I met Mr. Lubell, he typed "I'm going to fight them." I asked, "Who?" and he said, "My family. My wife." The whole time he was fighting to have Dr. Fiedor as his doctor. He didn't want Dr. Ruben because Dr. Ruben was very strongly suggesting that the nursing home would be best for him. He was communicating with me perhaps to get the word out to Dr. Fiedor. I was trying to support Dr. Ruben without losing Mr. Lubell's trust

in me. That went on for a while. As I got to know him more, we talked about other things. He mentioned his brother in San Diego who was a pediatrician because he found out that I wanted to go into pediatrics. We talked about lots of things. One time he asked me, "Where are you from?" and I said, "Iran." Then he said that he was Jewish, and we talked a little about this book he had gotten from Dr. Fiedor, *Maps of the Ancient World*.

He also did not like the resident, because the resident was agreeing with Dr. Ruben. About a week after I met Mr. Lubell, I began to sympathize with him. I said this guy's frustrated and he's not getting any response from these people, so maybe I will have a talk with the resident. The resident explained his point and put me in balance. Often-times I was caught between Mr. Lubell and the team, and I did talk to Dr. Ruben and the resident about this. They said don't let him put you in a tough situation. If he tells you something and he says tell me you're not going to tell this to anyone, you can't do that. As a professional you can't do that.

David Ruben, Attending Physician

I ACTUALLY TALKED TO OUR ATTORNEY because I thought I was going to have to go to court about the involuntary hospitalization. I felt it was the right thing to do because the guy continued to have the problem. He had been home, and it turned out he couldn't function at home. The attorney supported us and thought the lesser of two evils was to do that rather than let him go home again. I did put some time pressure on a number of people, which made them very angry. There was this inclination to just let it be. I stuck to a two-week period for making the decision. I felt that the only thing that I had control over was whether he stayed in the hospital or not, which made some of the staff really unhappy, infuriated. They felt I was putting them in a bind. But I was not willing to send him home. I had a number of conversations with people about it. How could I take the position that this person was impaired when he was so intelligent and was able to talk about everything on the machine in such a

beautiful way? This was true—he was very intelligent. Most of his mental capacities were intact. It was just in the area of his own relationships and his own self that he was highly impaired.

Cathy Smith, Social Worker

WE BEGAN TO LOOK INTO GUARDIANSHIP proceedings. Part of that process with any patient on the unit is that they have a right to an attorney and a right to attend the trial. Not only was I working with Mrs. Lubell and the family to get the guardianship thing under way and advise them about what I understood. I was also helping Mr. Lubell find an attorney for himself because he didn't want a public defender. He was determined he was going to fight this thing, and he wanted a good lawyer. That's fine. That's reasonable. I found a very good attorney through an agency that handles guardianship cases, and she came out to see him. She interviewed him at length, and it was her impression—as certainly it was my impression—that if there were any way to resolve this without going to court, that would be ideal. If there was any way the family members could see their way clear to make the decision to go to the nursing home without doing this guardianship, that would be in everyone's best interest. She said, "If he goes to court, he stands a pretty good chance of not being found incompetent. To have a 69-year-old man roll into court with a word processor and type in responses to what the judge asks him—that's pretty impressive."

Saman Pezeshki, Third-Year Medical Student

SO WE WERE TRYING TO GET POWER of attorney over Mr. Lubell by proving that he was incapable of making decisions for himself. But if he signed a letter giving Dr. Ruben the power of attorney, then we didn't need to go to court. On the morning of the court date, he hadn't signed the sheet, so that morning I went in with the resident, who took the sheet over to him. Dr. Ruben was waiting outside, and the ambulance was there so we could transfer him to court, but the resident wanted to give it a last shot. He went in quickly and said, "You need

to sign this, Mr. Lubell; otherwise we have to go to court.” Mr. Lubell—being the kind of person he was—of course wasn’t going to agree. This was a successful businessman prior to this happening and a very determined guy, so he wasn’t going to budge when someone tried to talk to him in a threatening manner. He didn’t sign the sheet.

Until then I didn’t know that he didn’t have to go to court if he signed it, so I asked the resident whether I could try to get the signature. The resident gave me a look like why are you wasting your time? I went in there and said, “Mr. Lubell, let’s put it this way. I know you’re angry, and I know that you are not happy with this decision. But if they take you to court, they are going to take all of your powers away, and they are going to decide what your outcome is going to be. Would you rather be in that situation, or would you rather sign this sheet and stay in power?” He looked at me and waved his hand that he wanted to write something, and I got him the sheet, and he signed his name. I went out and told the resident I had his signature, and he couldn’t believe me.

Cathy Smith, Social Worker

IT ENDED UP THAT THE PSYCHIATRIST worked very hard with Mr. Lubell to help him come to some acceptance and maybe begin to work on grieving the loss of his independence. Somehow I think through the work with the psychiatrist and having had an

attorney appointed to him and having his requests met, he felt in enough control that he could finally say, “Okay, I’ll go. I’ll go voluntarily.” It was a big relief to all concerned.

When he left, he kissed my hand and said, “Thank you very much.” He was really a very warm, very nice man. It was very sad for all involved.

One time I asked him what the big deal was about nursing homes, and he typed on his computer, “I will die if I go to a nursing home.”

—*Saman Pezeshki, Third-Year Medical Student*

Saman Pezeshki, Third-Year Medical Student

ABOUT A WEEK LATER he went to the nursing home. The social worker got involved, and they arranged for him to visit a couple of nursing homes. When I would ask, “How did you like it?” he would shake his hand saying so-so. He didn’t really like it, but he wasn’t against it the way he was

against many other things. He finally was assigned to go to the nursing home that he liked the most. At that time the wife would visit with him, so it wasn’t a lonely decision for him.

I remember him being wheeled off, and it was sad. It was probably the best thing for him. I can’t say for sure. It was sad that he had to go through all of that and go with the plan that he was fighting against. Then I didn’t hear much about him until I learned that he had passed away exactly two weeks after leaving the hospital. That was a shock. One time I asked him what the big deal was about nursing homes, and he typed on his computer, “I will die if I go to a nursing home.” ☹



Confrontation. Oil and acrylic on board by Merton Simpson, ca. 1965.

Photo: Merton Simpson Gallery, New York.

Commentary

Ms. Lubell's Complaint

(A Fictional Clinical Record)

Steven H. Miles

THE NARRATIVE APPROACH TO ETHICS differs from the principle-based approach both in the fullness with which it views personal characterization and in its tendency to focus on meaning as it is experienced rather than on the application of principles to a situation. The presentation of an ethics problem entails a somewhat arbitrary selection of a principal character, a choice that organizes other characters into dependent, supporting roles. A narrative ethics approach may imaginatively try to reconstruct the same clinical story, an approach I call *hypothetical narration*. A hypothetical narrative is an alternative arrangement of the known information which redirects our moral attention to perspectives or possibilities that may be understated or overlooked by the narrative organization of the case presentation.

Hypothetical narratives differ from the hypotheticals that are commonly used in principle-based ethics. Those hypotheticals tend to be sketches that distort a key feature of the case in order to delineate the operation or limitation of a principle in the case. For example, "Would the resolution of a problem pertaining to a terminally ill 95-year-old person be different if she were 17 years old?" Though a hypothetical narrative is not a historical reconstruction, its moral utility requires that it be factually plausible with regard to the possibilities inherent in the case under analysis. Used in case-story analysis, hypothetical narration should be a form of moral imagination rather than simple speculative psychobiography. It should attempt to articulate how the character and choices of various agents "make sense" or may be helpfully responded to. It should make the theater of moral action more complex and vital as it attends to complex life histories in the moral problem being presented.

Let me illustrate by presenting a hypothetical "clinical perspective" on the Lubell case, this one imagined from the perspective of Ms. Lubell, rather than Mr. Lubell, as the patient.

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Intake interview: Ruth Lubell

Program: Outpatient Counseling &
Women's Group #5

Interviewer: Germaine Ender, Psychologist,
Family Counseling Section

Ruth Lubell is a 64-year-old woman who presents with complaints of feeling sad, guilty, and isolated following the recent death of her husband.

Educational/occupational background: Ms. Lubell has a master's degree. She is a professor of art at City College and has a substantial reputation as a sculptor and teacher.

Family history: She was married for 40 years to a somewhat older man who worked in an accounting firm. She married young, before she had established her career.

She describes Mr. Lubell as an extremely controlling, emotionally distanced, impulsive, and emotionally and physically abusive spouse. Marital arguments were about Mr. Lubell's control and secrecy over family finances, his belittling of Ms. Lubell's career, and parenting.

Over the years, Mr. Lubell assumed control of the family finances, including her salary. He dissuaded her from having her own bank accounts. She had no credit history or personal investments aside from a university retirement account. Until her husband's death, Ms. Lubell had no idea how their money was invested. She has since learned of about a dozen different investment accounts, which she is now beginning to understand and to draw on to provide for her future.

She says that sculpting and teaching are the center of her life, in part because she got little respect at home. Mr. Lubell resented Ms. Lubell's success as a sculptor and as a teacher. He belittled her work, using his gregarious way of discussing his "hobby scholarship of ancient history" to mock her work.

Mr. Lubell physically abused Ms. Lubell. The first assault was 30 years ago. More often, he physi-

cally threatened her without actually hitting her. Physical assaults by striking or pinching were infrequent but unpredictable and impulsive. Ms. Lubell often felt threatened and afraid in their apartment. Mr. Lubell was taller and heavier than his wife.

She says she loved her husband and would have continued to live with him even though they had become increasingly estranged over the last 20 years. Mr. Lubell would not go to a marriage counselor with her. They never seriously considered divorce, because "people of our age married for life, for better or worse." Ms. Lubell believes that her husband would have vindictively impoverished her if she had left, a belief aggravated by her unfamiliarity with the family's finances. She believes that she would have been "blamed" for a divorce because he appeared so charming to people outside the family.

There are three children: two sons and a daughter. They do not live in town, and this is not a close family. Though not caregivers during their father's illness, they strongly felt that he should not be in a nursing home. Ms. Lubell is bitter that they visited him only once in the hospital a few weeks before his death. On that visit they showed up a day later than they had promised and commanded a hastily convened family conference because they "had to" leave two hours later.

Recent history: She says her symptoms date to events following her husband's stroke. The stroke had impaired his speech, and he responded to this disability with increasing anger and vindictiveness—mainly an exaggeration of his lifelong behavior, according to Ms. Lubell.

The last months of his life were managed by health care providers who did not know the family. Ms. Lubell feels that they made her husband's stroke the focus of their attention and did not appreciate her needs or the danger she was in as the stroke aggravated the entrenched and dysfunctional patterns of the marriage. She says the health care providers spoke mainly about his "massive loss," explaining that he could not "normally control" his

aggressive behavior. She feels they minimized his danger to her and her fear of him, even though he was often irate, insulting, and threatening in the hospital. She says that the doctors saw him as “pushy” but were unwilling to see him as “a man who abuses his wife.” Mr. and Ms. Lubell were finally separated when he was placed in a nursing home after he assaulted a home health care worker. This separation was followed by his death soon after.

Ms. Lubell feels that her experience, her needs, and her efforts to care for her husband were belittled throughout their marriage and during the last months of his life. She believes that she did everything she could for him. She says, “My husband had the diagnosis, and that meant that *his* needs and *his* pain became the point of the story of *my* life.”

For three months before his death and for the ensuing three months she has been crying in her apartment and having panic attacks. She is not sculpting. She has difficulty sleeping and wakes up feeling lonely and sometimes panicky about financial concerns, which she relates to her approaching mandatory retirement. Her children call infrequently. Ms. Lubell thinks they blame her for putting their father in a nursing home and for his death.

There is no family or personal history of substance abuse or depression. She is not suicidal.

Provisional assessment:

- Post-traumatic stress disorder
- Battered spouse
- Panic disorder, situational
- Bereavement

Dictated by: G. Ender 3/1/93

THIS HYPOTHETICAL NARRATION is necessarily controversial in several ways. Most superficially, it is controversial in the details that have been added to carry the hypothetical story. For example, I do not know that Mr. Lubell was heavier than his wife, but it is fair to imagine the possibility that she felt physically overwhelmed by him. I do not know whether the real Ms. Lubell believes that her

children hold her responsible for Mr. Lubell’s death, but it is fair and therapeutically important to imagine that this may be so and to inquire into this possibility. The hypothetical narration is also controversial because “Voices,” which focused on Mr. Lubell, did not present him as a spouse abuser, though comments about violence, threats, and in-

timidating behavior were repeated throughout. This is an important possibility, and one that physicians are often reluctant to see in middle-class families, with the result that treatment plans are inadequate, and further harm is done to victims.

One might ask, why tell a hypothetical narration? Why not just analytically present these possibilities? Clinicians think in terms of histories, stories. A story is not just “colorful”; it is a powerful way to organize and to interpret information. A story creates empathy more readily than does analytic discourse. Hypothetical narration suggests the significance of possibilities in the presented information; it motivates therapeutic insights and empathetically persuades the listener to take them seriously.⊗



After Visiting Hours. Etching by Niels Yde Andersen, ca. 1940.

Overview

“The Whole Story”

Kathryn Montgomery Hunter

AS A STORY COMPOSED FROM the richly detailed first-person accounts of six participants, “Voices” addresses the possibility that knowing more and knowing it from several different angles can help us better understand an ethically troubling situation. To meet the criticism that ethics cases are often too thin to serve as investigative data, Chambers has assembled a story robust enough for us to ask—and begin to answer—important questions about its interpretation. Yet varied and detailed as the narrative is, the voices of the patient and his wife of 40 years are missing. In this, “Voices” resembles all too many more ordinary ethics cases. Short stories and poems, movies and anecdotes customarily fill in these missing accounts in our moral education (Booth 1988; Nussbaum 1986), supplying us vicariously with the experience of illness, helplessness, old age, or the downward course of an incurable or irremediable disease. Here, in “Voices,” by assembling the narratives of those who cared for

Mr. Lubell, the author attempts to repair the loss within the case story itself. “Voices” replicates the work of a reflective health care team, doing the best it can in the absence of complete information. There is no satisfactory ending, and although the Lubells’ missing narratives might add to our understanding, I do not believe that our having “the whole story” would of itself lead us to an unshadowed or even a very satisfactory conclusion. That is, I want to separate my belief in the value of fully detailed ethics cases, particularly the stories of the people most affected by the troubling situation, from the quite different belief that a complete narrative either is possible or is an unalloyed good. “The whole story” may serve as an ideal in the limited world of medical narration, but even if such a story were accessible to us, it would not necessarily answer all our questions about the right care for this troubled patient.

Because Mr. Lubell’s situation is a sadly common one for aging victims of stroke, others may feel they know his story, but he is represented here, as he often was during his illness, in the accounts of his caretakers and in the scratchy, labored notes he wrote in an attempt to assert some control over his life. We are given the first resident’s story, the psychiatrist’s

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story, the social worker's story, and the neurologist's story; then, after Mr. Lubell's second admission to the hospital, a second resident and a third-year medical student join in. All told, there are four physicians (two well established and two early in their careers), one experienced social worker, and one medical student; all but the neurologist are part of the psychiatric team taking care of Mr. Lubell. In their accounts of his illness they tell about Mr. Lubell, his wife, his three children, even briefly his lawyer, and at times they reflect one another's presence as they play their parts in the hierarchy of a hospital staff. Although these first-person stories are not, except indirectly, about their tellers,

we gain a sense of who they are: Dr. Rouel, the woman resident, is drawn to Mr. Lubell, taking professional note of his muted but defiant, perhaps ironic, sexual aggression; Ms. Smith, the social worker, has seen many cases like this, although this one is also clearly different; Dr. Ruben, the psychiatrist, seems troubled, his customary abilities frustrated; Dr. Fiedor, the neurologist, has an outsider's simpler view of the problem; Dr. Lopez, the second resident, reflects on cultural and religious differences that, he implies, might make a difference in the patient's response; the student, Saman Pezeshki, tests the balance between professional detachment and his interest and involvement with the patient.

As a composite account, "Voices" challenges the inherent subjectivity of narrative ethics by replacing the customary single narrator, who may choose to report multivocally what has been learned from others (see Bakhtin 1981), with, literally, the voices of multiple witnesses. Their juxtaposition can be as enlightening for what it reveals about people who ostensibly agree as for its exploration of radical differences. Here, as the members of the psychiatric

staff struggle within themselves and with their differences as members of an educational and management hierarchy, they express those differences indirectly. They pose them as a learning issue; they attribute them to a physician external to the team; they embed them in their stories as narrative breaks and sudden time-leaps to an unwanted outcome.

These struggles go far beyond a conflict of bioethical principles, a conflict between Mr. Lubell's autonomy and the staff's attempts to act for his welfare. Their beneficence displaces their indirect acknowledgment of the drain on time and energy, staff resources, hospital beds, and a rational health care budget that the patient comes to be. Members of the

staff are troubled by the conflict he represents, their failure to resolve it more readily, and, above all, their inability to help him. When he leaves their care abruptly, it is not because the team or any of its members give up on him or abandon him, but because another physician, responding to his anguish and unfamiliar with (or discounting) Ms. Lubell's view of the matter, allows him to go home.

Through it all, Mr. Lubell's wishes are clear. He wants to be himself again. Barring that, he wants to go home and take care of himself, or, if necessary, have his wife take care of him—despite her unwillingness and his impulsive violence, despite her age and size, despite whatever there may be of their history that we do not know. But without knowing the Lubells' stories or, more directly, the story of their life together, how are we to understand what we do know? The standard for good science applies as well to good narrative: can it be tested? does it contain some indication of its own limits, the germ of its own possible refutation? For a story, the test lies in our awareness of the narrator's bias and the ever-present possibility that confounding details or

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alternate interpretations will unfold. If someone else were to tell this story, would new light be shed on the problem? Would we have new information that might explain everything? Or would an alternative interpretation undercut what we think we know, throwing it into chaos?

In “Voices” we have evidence that the psychiatric team tested for just such an alternative story. Did Martin Lubell physically abuse his wife before his illness? Apparently not. Was the marriage a good one? It had lasted for 40 years, a fact that does not answer the question. In the details of her career and the reports of their children we have hints of what Ms. Lubell’s untold story might be—bits of information we will interpret in light of our own ongoing life stories. But finally—even with such a thickly detailed story—we are left knowing that we do not know everything.

From the story we do have, one event stands out. The medical student, Saman Pezeshki, was able to persuade Mr. Lubell—perhaps by misrepresenting his chances in a court of law—to sign the consent form for his transfer to a nursing home. During his psychiatry clerkship, Pezeshki spent time—that scarcest of all resources in medicine (and, clues suggest, in the Lubell family too)—talking to the patient, reading his computer screen, waiting for the painfully written words he scrawled on paper. At first he saw the situation Mr. Lubell’s way, but then, deciding to bring up the matter with the resident, he was admonished to keep his balance, “not to let the patient put you in a tough situation.” At the last possible moment before Mr. Lubell left for court to defend himself against the appointment of a guardian, the student went back to ask him to sign the consent form, acknowledging his anger and posing the question in terms of the power that remained to him.

It is doubtful that he said something no one else had said. The people who cared for Mr. Lubell included a skilled and experienced social worker, two capable psychiatric residents, and a good, self-critical geriatric psychiatrist whose skill, even in the “disastrous” family meeting, is affirmed by the resi-

dent (traditionally a ready source of criticism). All sympathized with Mr. Lubell at one time or another, and several remark that they might be the same if they were to suffer a stroke. Their seeing him as “like us” highlights the issue of his power rather than obscuring it, and his lawyer in particular was committed to preserving his autonomy.

Was it simply that the time was right? Certainly the resident’s attempt to gain Mr. Lubell’s consent had failed just a few minutes before. But the ambulance was at the door. And though his lawyer had certainly assured him of the strength of his case, Mr. Lubell, impaired and potentially alone, may have hesitated to go out into the world of courtrooms and judges and certificates of incompetence. In that moment, Saman Pezeshki expressed both concern and fear and offered an alternative, empowering version of consent. Or was it the student himself? He was young, an acknowledged learner. There is every possibility that Mr. Lubell saw him differently—and saw himself as his teacher, or at least as a part of what the student had been assigned to learn. Saman Pezeshki had listened. Then, too, he was an Iranian, a Muslim to whom Mr. Lubell, a Jew with a scholarly interest in history, had become attached. Perhaps that made the student’s final appeal even stronger. In relation to the young man, a newcomer who was for this patient especially “other,” Martin Lubell was an adult, a man still in the world, a person whose actions still made a difference. He signed the paper.

This event reminds us that Mr. Lubell’s friends are also missing—not only from the roster of narrators but also as characters in any of the accounts. We have no sense of the stories that must have been told about his predicament by those outside the hospital, stories that might allow us to understand more exactly his rejection of a nursing home, even on a trial basis. We think we understand it: no one likes nursing homes. But we do not know its exact associations for him in his community, in his circle of friends. Friends seem to be missing also from his bedside. We have no indication that there was anyone who might have refined his sense of his

situation or suggested that some nursing homes or some circumstances might be exceptions to his apparently inflexible rejection. Mr. Lubell even relies on the social worker to engage an attorney to defend his competence rather than calling on someone from his prehospital life. He compels everyone's attention to the labored process of communication. Only a medical student, at least as we have the story, has time to respond. Only the student succeeds in persuading him to exercise the power to choose a nursing home.

There is no hint in what we have read that a friend or a rabbi might have been as persuasive as Saman Pezeshki—or any quicker; and no relative stepped forward with another alternative for Mr. Lubell's care. We are left with a story of crossed purposes and misunderstandings. Good, competent, well-motivated people disagree about how to respond to the problem posed by Mr. Lubell's refusal to go to a nursing home and Ms. Lubell's unwillingness to take care of him at home. Was he a captive in the psychiatric unit? They refused to send him home without the assurance of adequate care, and their predictions seem to have been confirmed when he was allowed to go home and soon was back again. Was the psychiatry staff rejecting him, pushing him out? They surely were aware, as every hospital employee is these days, of the limits on beds, staff time, insurance payments, family resources. And, past a certain point, a hospital is not a healthy place to recover from a stroke.

Would we know more if we knew Ms. Lubell's story? or if Mr. Lubell had recorded his account of his medical care on his computer or printed out his messages? if we understood their children? if we knew why his friends aren't visible and how they might have understood his predicament? Of course we would. But some stories are now inaccessible, and others we have no right to know. We know enough. There is little reason to believe that the stories we do not know would "explain everything."

MEDICAL CASES HAVE LONG BEEN CRITICIZED for their narrowness and "dehumanization," even

though, as patients, we value the clinical expertise and the nonjudgmental acceptance of human frailty that distance and professionalize physicians' accounts of patients' maladies. Recently, bioethics cases have come in for much the same criticism and for some of the same reasons. As bioethicists have wrestled with questions posed by advancing technology in a pluralist society that prizes individual choice, they have sought guiding principles that could be generally and objectively applied, even across cultures (Engelhardt 1986; Pellegrino 1993). But critics claim that this is to be scientific—that is, scientific about matters not amenable to scientific rigor—and to ignore the inescapable cultural, familial, and personal situatedness of moral knowledge. An ethical science, these critics hold, is no more possible than a science of history: in both fields generalizations grow weaker as they are broadened to apply to more and more instances. In addition, the principles-based ethics that for the last 25 years has been all but synonymous with bioethics has met with such success in its critique of medical practice that it has been adopted—some would say co-opted—by medicine itself. In the process, principlism's attention to the balance (and the potential conflict) among the principles of patient autonomy, medical beneficence, the physician's duty to do no harm, and social justice, while still powerful, is sometimes flattened in hospital practice to a veneer for unexamined habit. When, as happens in some courses and textbooks, ethics cases are used as didactic illustrations rather than data to be investigated, we must ask, as we have learned to do for clinical cases, where the patient's story is to be found (see, for example, Arras 1991; Donnelly 1992; Chambers 1994). Despite the inherent difficulties of coming to know a patient once he or she is sufficiently anomalous as to become a "case," the new contextualists in bioethics attempt either to resituate the discussion of the patient in the world of lived experience or to restore the tension between cultural values (including the principles of medical ethics) and real life events that test and refine those values (see, for example, Jonsen and Toulmin 1988; Reich

1987; Zaner 1988; Sherwin 1992; Brody 1988; Miles and Hunter 1990).

Narrative ethics, the approach explored in this Case Stories series, attends to the contexts of moral choice: its history and present circumstance and its personal meaning. Rather than asking what decision ought to be made in a given instance, narrative ethics poses H. Richard Niebuhr's question, "What is going on here?" (1963) and answers first with a careful reading and interpretation of the available story and then with appropriate and responsible action. Because narrative depicts events embedded in the lives and ongoing concerns of its protagonists, it represents moral choice not as a snapshot but as an unfolding web of character and motivation, luck and circumstance—with all the apparent nonessentials that give human beings their sense of identity (Burrell and Hauerwas 1977; MacIntyre 1984). In its representation of subjective experience, narrative gives us access to the perceptions and valuations of other human beings, and thus narrative bioethics is a means of thinking about the meaning of illness in the life of the patient and about the role of the physician in the patient-physician interaction. Above all, narrative ethics acknowledges the situatedness of human understanding through its concern with the case narrative itself: the occasion of its construction and presentation, the identity of its narrator, its forms and purposes and assumptions. Readers are unavoidably drawn to make inferences about the telling of the story, including whether the narrator shapes the story to include—or ignore—culture, history, life stories, power relations, economic conditions, and personal entanglements in the present situation. Ethical discourse begins with

a consideration of these matters. We are not promised certainty or completeness about any of them, but they cannot be ignored.

The goal of narrative ethics is not "the whole story"—not even as an unapproachable ideal. Although it might seem the goal of all storytelling, the idea of "the whole story" paradoxically encourages the reductionism and omniscience that narrative ethics attempts to subvert, and it runs the risk of authorizing the invasion of another's life (King and Stanford 1992). We can work toward richness and balance in both telling and interpreting, but the whole story necessarily escapes us. Another reader, another author, could always tell us something more.

Not all stories end happily, despite the best efforts of dedicated people. Nor does a "happy ending" guarantee that the problem has been solved—or, for that matter, that it has been well addressed. "Voices" not only demonstrates that rules and principles would be a mere sketch of a protocol for action in the absence of a well-constructed, well-interpreted narrative; it also suggests that even where good narrative accounts of the situation exist, we have no guarantee that the "right" decision will be obvious or easy to act upon. We may have only a humbling sense of what can go wrong in human interaction and, perhaps, a better sense of how to prevent or address such situations in the future. This means, first, taking into account quite early the values and life stories of those who are most affected by the patient's illness, then understanding the patient's illness and hospital course as an integral part of those life stories, and, above all, representing the situation to them not as a "problem" to be solved but as a crucial life event to be integrated into those stories.

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"Voices" is not *Rashomon*, Akiru Kurosawa's 1951 film that confounds its viewers with four radically different, irreconcilable accounts of a rape and a murder, three by the principal characters and one by an apparently impartial but no more credible witness. Yet, like *Rashomon*, it raises the possibility that the truth cannot be known even if all the stories are told, all the "facts" assembled. Just as ethics cases do not contain a kernel of pure knowledge that could be revealed if only the circumstances were stripped away—the principlists' position—neither will the aggregated stories, the views of all the participants, add up to a solid representation of the pure and unalloyed truth.

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Stories are constructed and presented by human beings in an effort to understand and be understood or, sometimes, to hide themselves and what they have seen; and while "thick" is better for the representation of meaning in human affairs (Geertz 1973), the interpretation of any narrative, whether thick or thin, is very complicated. We sort through the stories we hear, testing them, wanting to know more or feeling satisfied that they fit or confound our general rules. In its subjectivity and in its transaction with other stories and the lessons we have learned from them, narrative represents openly the tentative, perspectival conditions of moral discourse. ☉

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Here It Comes Again. Acrylic and pastel by Gerard MacKay, ca. 1988.

Sandoz Pharmaceuticals Corp., "Through the Looking Glass" headache art collection.

Leonard

C. Bryant

How you are fallen from heaven, O Day Star, son of Dawn!

—*Isaiah 14:12*

THE AMBULANCE TOOK LONGER THAN USUAL because someone half asleep at the wheel of a red pickup truck, an unshaven cowboy with a large Stetson and a beer belly, thought he was hearing things—his wife’s shrill voice, the high-pitched screech of his son’s electric guitar. The cowboy stopped in the middle of the road for the red light. Riding up his back fender, the ambulance screamed reproach. When the light turned green, the truck careened to the curb, and as the other vehicle rolled by, both drivers glared at each other and cursed.

The people who lived in the apartment building leaned over their railings, and the pots of petunias and tomato plants tottered as the ambulance pulled up the driveway.

“How far did he fall? From which floor? Is he a resident of this building?” The policeman, officious and important, ordered onlookers to stand back, wrote things down, radioed the station, directed traffic, escorted the ambulance. His first suicide.

LEONARD, HOWEVER, WAS NOT DEAD. He had fallen into the apple tree from the fifth floor. Broken bones and lacerations, but no orthopedic surgery required. Just a chat with Dr. Strongfield.

The doctor shook his head when they brought him into emergency. “Not again.” The two men were the same age, but one was a psychiatrist in a large teaching research hospital, and the other survived on a disability pension. One lived in a sprawling house in Riverbend, a prestigious part of Edmonton. The other lived in a basement apartment where he had to peer up in order to see the sun coming through the grate, where spiders crawled in between the cracks and wove their webs in the corners between the lamp and the bookcase. Some people think that schizophrenia is an artist’s disease, and that out of the torment comes genius, poetry more musical than Blake’s, paintings more sensual than van Gogh’s. But the doctor knew differently. “Not as bad as last time, Leonard.”

Last time was off the High Level Bridge. That night Leonard had decided to fly into the moonlight. Silver fragments on the river beckoned. Leonard thought that if he fell into the moon on water he would cleanse himself of sexual thoughts, undergo

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a baptism before death, purification by drowning.

After he got out of the intensive care unit, Leonard told the doctor that the last thing he remembered seeing was two lovers kissing. He waited until they were finished and had strolled away arm in arm, their two heads one silhouette; then he climbed over the rail and jumped. They must have heard his body hit the water. No scream.

They called the rescue squad.

"That was no favor," he said to the doctor. He couldn't remember a time when he didn't want to die.

Dr. Strongfield planned aggressive treatment. After Leonard got out of the intensive care unit, the doctor ordered six courses of electroconvulsive therapy (ECT). That had been 10 years ago. Very few of his patients underwent that sort of therapy, but he was so frustrated by his failure with Leonard that he was ready to try anything. Sometimes the psychiatrist thought that he, too, was possessed. He couldn't give up caring for Leonard.

Once he had heard two nurses gossiping in the hall. He had come upon them as they were waiting for rounds at the patient's door. Leonard had tried to shoot himself in the face, but at the last minute the gun had misfired.

"Maybe there's been mental illness in the family. A son? A brother? Someone close to him that couldn't be helped," they said.

Strongfield had been mildly suicidal himself after his wife died from leukemia at the age of 41. Relatives and friends had set him up with divorcees and widows of different shapes and ages. But he never married again. Nor did he become a man about town. Most of the nurses talked quite openly about whether they found him attractive, even though he was steadily gaining weight. He knew they gossiped about him. He realized that any of them would gladly go out for a drink on a Friday, eventually cook

dinner for him on a Saturday, and in a few weeks spend the weekend at his place.

He missed a woman's presence, the odor of her body, the feel of her skin against his, her hairpins in the bathroom sink, bottles of makeup on the table, the clutter of a woman in his home. But no one ever measured up to his wife. No one made him feel as comfortable, understood his little needs. She knew

when to listen and when to be silent, how he liked his steaks grilled, and how much soda to add to his scotch. Eventually he gave up and told his friends to stop trying to find suitable partners. He survived on memories. For a time after her death, he drank heavily. He sat in front of her picture, sipped scotch, listened to the clinking of ice, and pre-

tended it was her voice. Sometimes they carried on conversations. Although he never broke the silence, his lips moved.

Dr. Strongfield met Leonard at the outpatient clinic after he had been discharged from the hospital. During the initial interviews he discovered that his new patient had no memories of his childhood, only a few dim flashes like clips from an old black and white movie.

"I remember my mother leading me by the hand somewhere. To school? To the doctor?"

Dr. Strongfield never made notes in front of his patients. He scribbled them later. Sometimes he spent the evening musing about Leonard in front of the fire in his study. He wrote on a scratch pad, "Feelings Leonard has about his mother: warm, safe, sad, sweet-smelling. He remembers the curve of her breast, sitting on her knee, slipping his hand into the V of her blouse, feeling the heat from her body, her skin, her singing, rocking, a lullaby, a verse." He recalled Leonard's rambling monologue in his office.

"Jack and Jill fell down the hill. My mother was as pure as the Virgin Mary, and yet she begat me.

**"I'm tired of having
the devil in me.
I've rented an apartment
on the eleventh floor.
I'm going to jump."**

She was not as pure as the Virgin Mary. She lay with my father. I never knew him. I have not lain with any woman. No woman has lain with me. Jack fell down and broke his crown, and no one came tumbling after."

FOR YEARS LEONARD LIVED WITH HIS MOTHER, a long-suffering widow who was devoted to her only child. She visited a plethora of clinics, case workers, and social workers; read avidly about schizophrenia; and consulted doctors. She struggled through early years when they suggested, never overtly, of course—the downcast eyes, the clearing of the throat, the troubled frown that turned quickly into a condescending smile—that she was the cause of his illness. "Of course I wouldn't for a moment suggest, Mrs. Griffin . . ."

On behalf of Leonard she begged Dr. Strongfield to give him the experimental drug. Though he became septic and nearly died from it, both mother and doctor comforted each other with assurances that everything had been tried. "I don't want to leave a stone unturned," she had said, standing solidly in front of his desk in her strong black oxfords, even though he had offered her a chair. When she died, her son jumped from the fifth floor of his apartment building and landed in an apple tree.

Rationally, the doctor knew there was no cure for Leonard. But like his friends who wanted to ease his loneliness he hoped to make life bearable for Leonard, to provide some comfort, however small. The hospital had a revolving-door policy. The staff knew the patients would return. They anticipated it, made provision in the long-term-care and discharge plans. Between the hospitalizations and bouts of madness, the doctor hoped Leonard might experience some semblance of normality, some little opportunity to be like an ordinary person with all the unappreciated glory of a prosaic life.

He thought about Leonard when he got up in the morning and made fresh coffee, listened to it bubble through the percolator, savored the taste. It was a little privilege but a precious one—to make coffee in one's own pot, to drink from one's own cup

in the privacy of one's own kitchen, to smack one's lips and say, "Yes, that's the best I've made."

Leonard Griffin: 1973–91, 11 suicide attempts

- 2 hangings
- 4 overdoses
- 2 stabbings (1 to abdomen, 1 to chest)
- 1 gunshot wound to face
- 1 jump off the High Level Bridge
- 1 jump from the fifth floor of an apartment building

Treatment

- 6 courses of ECT
- 10 different antidepressants
- 3 mood stabilizers
- 5 antipsychotic medications
- 8 different rehabilitation programs
seen as outpatient

When Leonard walked into the office on June 6, he wasn't expected. But the nurse knew him so well that she let him in without an appointment. The doctor looked up from his notes and smiled. He noticed Leonard was clean shaven and wore a suit and tie. He looked to be in excellent health and in remarkably good spirits. The doctor asked the nurse to bring them both some coffee.

"You're looking good. What's up?"

"I came to say good-bye."

"Good-bye?"

"And to thank you for trying so hard. You're the only one in the world who cares about me."

The doctor nodded. "Yes. I care." He leaned forward in his chair.

"I'm tired of having the devil in me. I've rented an apartment on the eleventh floor. I'm going to jump."

"It's that bad, is it, Leonard?"

The patient nodded gravely. Then he extended his hand, and the other man rose from behind the desk and took it in both of his. They held onto each other in that formal way for a few moments as men often do when they are too moved to speak or do not know how to mouth the words of love and despair.

The doctor broke the silence first. "Good-bye, Leonard."

WAS DR. STRONGFIELD TOO EMOTIONALLY involved in the case to realize that his patient was improved because he had decided to end his life once and for all? Was the doctor in a state of denial when he let him walk out of the office? Was this visit by the patient a final cry for help? Shouldn't the doctor have apprehended him immediately or himself taken the patient to the nearest emergency unit?

These are the questions the hospital's bioethics committee asked after Leonard terminated his life by jumping off the balcony of his apartment. The president of the hospital had asked that they explore the case as part of the quality improvement program. "There is no wish," he said, "on the part of any of us to cast blame, formally to censure or even caution Dr. Strongfield about his apparent passivity, dare we say neglect. But it is a classic case, and there is the possibility of a lawsuit—not in this case, of course, as there are no living relatives. But on some other occasion we want to be assured that everything will be done for a patient in this hospital."

The social worker was more concerned about the people on the street when his body came crashing down, splattering blood on the concrete. "After all, we have a responsibility to the community at large as well as to the individual patient," she said. The philosopher from the university talked about the principle of nonmaleficence, and the medical chief of the intensive care unit spoke of the hospital's

mandate to save life. (Earlier that afternoon he had drafted a letter of discipline to the Canadian Medical Association and then on second thought had crumpled it up and thrown it in the wastebasket.) Only the chaplain commented somewhat apologetically that the patient had found peace and that perhaps, considering the circumstances, he had suffered enough.

Through it all, Dr. Strongfield kept quiet and spoke only when addressed. He directed his young resident to introduce the case and give the pertinent details of the treatment and relapses. He knew enough about the psychoanalytical approach to make his face into an inscrutable mask, to grunt at the appropriate moments, and to avoid eye contact. The only giveaways to his own uncertainty or tentative guilt about the decision he had made were occasional attempts to clear his throat, which had become dry and thick with mucous from an embarrassing nasal drip.

That night after a cold, unsavory dinner he retired to the library. He settled into his favorite chair that bore the permanent imprint of his body. As he sank into the cushions, they seemed to enfold him. He glanced at the photo of his wife. But he neither picked up a book and pretended to read nor bothered to turn on the TV so that the news announcer's voice would fill the void. The only sound in the room was his own labored breathing and the tinkle of ice in his scotch and soda. "To you, Leonard," he said, raising his glass to the starry sky. "Peace." ☸

NOTE

The writing of this fictional account was prompted by the deliberations of a hospital ethics committee.

REFLECTION

Learning the Hard Way

Mark D. Fox

"AMAZING GRACE, HOW SWEET THE SOUND . . ." From high in the balcony, the haunting wail filled the void of the chapel. We had gathered to remember our friend and classmate, to celebrate his life and to acknowledge our grief at his death. For those of us apprenticed to this profession of healing, it was an opportunity to reflect on the lessons of the previous six months and a challenge to integrate them into our practice of the art.

"The patient is a 25-year-old white male medical student whose present illness dates to approximately one year prior to admission." Medicine was his vocation and sports his avocation: to play or to watch, whatever the sport, whatever the season. A distance runner and basketball player, Dan had wanted to "put some meat" on his lanky frame for quite a while. He added the weight room to his training regimen, to no avail. Nutritional supplements did not help either. But he continued to run and play with the same vigor, the same enthusiasm.

The long hours of the third-year clerkships in medicine and surgery curtailed his athletic training somewhat but confirmed his decision to pursue a career in medicine. He thrived on the wards. He enjoyed caring for patients, and his easygoing, reassuring manner put patients at ease. The long hours were wearing on him, though. He was fatigued; he didn't feel good. He wasn't getting enough exercise, and he

wasn't gaining any weight. Still, his enthusiasm—for life, for medicine, for sports—never waned.

With the new year came a lighter schedule of clinical rotations, with fewer and less demanding nights on call. Dan got back into his training rhythm. He found his calling in obstetrics and gynecology, with the perfect blend of primary care and surgical intervention. Delivering babies was icing on the cake. Plans were also in the works for his long-time girlfriend to move to town, and there were whisperings about a wedding in the not-too-distant future. Things were definitely looking up, and the future looked very bright indeed. Still, he did not feel well.

"The patient presented to the Student Health Service for evaluation of fatigue and failure to gain weight over the past year despite efforts to do so with adequate caloric intake and nutritional supplementation." He had no specific somatic complaints. He didn't feel particularly bad, but he didn't feel well either. The history and physical didn't get them very far, so they drew some blood and told him to check back the next day. As he looked up the labs on his patients that afternoon, Dan checked his own labs as well. His white blood cell count and electrolytes were normal, but his PCV¹ was low; the rest of his labs weren't out yet. He picked up a few hemocult² cards and some developer as he left the hospital that evening.

"Physical exam was unremarkable. Laboratory evaluation included normal electrolytes and normal thyroid functions. His liver enzymes were moderately elevated. CBC³ revealed a normal white count but marked iron-deficiency anemia." When he called the Student Health Service the following day, Dan learned that his liver function

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Beside the Dead. Lithograph by Ben Shahn, 1968.

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tests had also been abnormal. They wanted to draw more blood, and they needed to find out why he was anemic. The physician had begun to formulate a differential diagnosis;⁴ the medical-student-turned-patient was suddenly working on one, too. A chronic, subclinical infection—hepatitis, maybe cytomegalovirus (CMV); and maybe gastrointestinal bleeding to explain the anemia—not uncommon in medical students.

"Stools were guaiac negative times 3.⁵ Serologies for hepatitis A, B, and C, Epstein-Barr virus, and CMV were all negative." Residents and medical students frequently bemoan the fact that patients who are not particularly ill are admitted to the hospital. It seemed ironic, then, that a well-appearing young medical student was being admitted to the University Hospital; there was, however, a growing dread that, although Dan seemed well, his body might be terribly sick.

A CT scan heightened the anxiety, for Dan and his family certainly, but also collectively for our class. The scan was quickly followed by a liver biopsy and a search for the primary tumor. "*The diagnosis of gastric carcinoma with metastases to the liver was confirmed by endoscopic examination.*"

We felt as though we had been run over by a "zebra."⁶ It simply could not be. Gastric carcinoma is not a disease of young men. The futility of the academic debate, in this case designed to shuttle over the emo-

tional turmoil, was readily apparent. Over the course of our year of clinical training, many of us had become calloused, some apparently immune, to the "bad news"—the grave conditions and poor prognoses—regularly distributed in ward medicine. Our mentors tell us we must maintain emotional distance to protect our humanity in the face of such tragedy. "*The patient elected to receive palliative care. He expired at his family home in early October.*"

Sir William Osler, M.D., defined his philosophy of medical education with this statement:

In what may be called the natural method of teaching the student begins with the patient, continues with the patient, and ends his studies with the patient, using books and lectures as tools, as means to an end. . . . It is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself. (1903:50)

When a friend becomes a patient, the protective facade crumbles. His bad news is our bad news. The experience forces one beyond the data of laboratory studies, beyond the objective study of disease. To confront one's friend in the texture of illness—to live *that* experience—provides a powerful opportunity for learning the art of medicine, the healing art. ☉

NOTES

1. PCV = packed cell volume. Also commonly called hematocrit.
2. A rapid test to detect occult blood in the stool.
3. CBC = complete blood count.
4. A *differential diagnosis* is a list of possible diagnoses on the basis of signs and symptoms they have in common.
5. Guaiac is the reagent used in the hemoccult test. A negative test indicates there was no occult blood in the sample. The test is often performed on three consecutive stool samples.
6. There is a saying that academic medicine trains people, when they hear hoofbeats, to think of zebras instead of horses—that is, to think of what is more uncommon than common.

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ON THE BIOETHICS FRONT

Particularly where individualism flourishes, as in the United States, people offer many reasons for separating themselves from others. Nancy Cummings here explores one such reason, the need to maintain confidentiality. Computers and fax machines are making available to an ever widening circle devastating information about people's genetic shortcomings and HIV/AIDS status. The danger of revelation reaffirms for many the importance of shielding people from others. Yet cannot the risk to others of *not knowing* become so great—particularly where AIDS and identifiable hereditary diseases are concerned—that it overrides the need for personal protection? Kathleen Nolan examines a different situation in which people separate themselves from others—when disabilities are involved. According to Nolan, we need to identify disabilities and deformities as different and inferior if we are to take advantage of opportunities to avoid them. Yet we do so at a tremendous cost. To brand weakness and imperfection as “different” and “expendable” is to tell the lie that we ourselves are both strong and perfect. It is ultimately to cut ourselves off from the care of others. Cummings, then, reminds us that if we overemphasize distancing ourselves from others, we may harm others. Nolan adds that we risk harming ourselves as well.

—John F. Kilner

Patient Confidentiality

Nancy Boucot Cummings

Brian Hoffman. 1990. “Patient Confidentiality and Access to Medical Records: A Physician’s Perspective.” *Health Law in Canada* 10:210–12.

J. F. Keenan. 1993. “Confidentiality, Disclosure, and Fiduciary Responsibility.” *Theological Studies* 54 (March): 142–59.

Claire C. Obade. 1991. “Whisper Down the Lane: AIDS, Privacy, and the Hospital Grapevine.” *Journal of Clinical Ethics* 2:133–37.

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In February 1993, the Task Force on the Privacy of Private Sector Health Records, Department of Health and Human Services (DHHS), held a conference titled “Health Records: Social Needs and Personal Privacy” (Task Force 1993), which addressed ethical, legal, medical, and research concerns associated with the issue of confidentiality. Although this is an issue of central importance, the recent literature on this subject is relatively sparse, especially in the U.S. Countries with national health programs and their accompanying data banks have paid a good deal more attention to privacy issues: Great Britain (Black 1990; Markus and Lockwood 1991), Canada (Ferguson 1990; Leadbeater 1990), and Australia (Riches 1986) have passed legislation to protect privacy in health affairs as well as in other arenas. South Africa (Van der Poel and Smit 1985) also has noted some of these privacy issues. Increasing dependence upon computers, along with concerns about autonomy, justice, and confidentiality (especially in regard to diseases

like AIDS and multiple drug resistant tuberculosis [MDRTB]), has made questions of access to records and the relevance of privacy particularly important.

Brian Hoffman, a Canadian psychiatrist, treats four topics: access to information by patients, access to medical records, problems, and restrictions. He recognizes that in order to make informed health care decisions, patients need necessary medical information, which usually comes from discussions with their physicians, but he questions whether a patient should have access to physicians' records or his or her medical records. Hoffman quotes the Public Hospital Act of Ontario's list of those who may inspect and receive information from medical records relating to patient care: an attending physician, a dentist, a person with a written request from the patient, a personal representative of a deceased patient, a parent or person with lawful custody of an unmarried patient under age 16, a member of the medical staff to use in teaching or in carrying out scientific research approved by the medical advisory committee, or any person for purposes of scientific research.

Hoffman notes that although the Krever Commission stated that "confidentiality belongs to the patient" and that "the patient controls access to medical records pertaining to him or her," the records do not belong to the patient, who can neither take them nor destroy them. Thus while a patient can expect that his records are confidential, the patient cannot expect to control the use of records pertaining to his medical or psychiatric care by relevant health professionals. Hoffman further notes that "in the interest of privacy some patients may be harmed as they undergo unnecessary investigations" because physicians and hospitals have failed to exchange information important to care of the patient either in the physician's office or during a hospital admission.

Hoffman's observation that "too many people" have access to hospital records seconds clinical ethicist Mark Siegler's thesis that "medical confidentiality, as it has been traditionally understood by patients and doctors, no longer exists" (Siegler 1982:1518). Siegler, after a patient expressed concern about the confidentiality of his hospital record, scanned his medical chart and enumerated "at least 25 and possibly as many as 100 health professionals and administrative personnel . . . [who] had access to the

patient's record," all with legitimate reasons to examine the chart (Siegler 1982:1519).

Hoffman cites two problems: the dilution of the medical record as a means of communication between the doctor and health care workers, and the substitution of patient access to records for a good physician-patient relationship. The five theoretical benefits for a patient who reviews her medical chart are increased knowledge; increased power of decision making and autonomy; sense of importance and self-esteem; sense of trust in the physician; and increased legal rights. He agrees that if patients have access to their medical records, they should be authorized to release them to others as appropriate.

The dilemma of when to protect privacy and when to protect society and the related health of the public sector are highlighted by the potential menaces of the AIDS epidemic and by the resurgence of tuberculosis, especially MDRTB. Two aspects of violation of patient confidentiality—release of information on medical records and casual discussions around hospitals and medical offices—have major ethical dimensions. Increasingly, the ethical aspects of these violations have been emphasized by the courts and by legislation aimed to protect both patients and society.

Claire Obade, a lawyer, discusses the legal and ethical ramifications of violating patient confidentiality. She emphasizes the common law acceptance of the fiduciary relationship of the health care provider and the patient—a relationship that traditionally and characteristically has been assumed, even when not expressed. Obade says that "the provider has a duty to keep information learned in the context of the [professional health care] relationship away from public or other improper scrutiny." In legal parlance, breach of this trust provides ground for action in tort for damages such as could be brought in malpractice suits.

Obade reminds the reader of the historical and current professional ethical standards concerning confidentiality. Hippocrates stated that "whatever in connection with my professional practice or not in connection with it (that) I see or hear in the life of men which ought not to be spoken abroad I will not divulge as recommending that all such should be kept secret" (in Reiser et al. 1977). The American Medical Association's Code of Ethics states that "the informa-

tion disclosed to a physician during the course of the relationship between physician and patient is confidential to the greatest possible degree" (AMA 1989, 5:5). The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) accepts the dictum that the "patient has the right, within the law, to personal and informational privacy."

In the U.S. it is the legal system, through both the courts and the legislatures, that has established rules of behavior about privacy. The famous case in which the Supreme Court addressed privacy regarding contraceptive decisions was *Griswold v. Connecticut* (1965). Numbers of states and the Supreme Court have recognized the right of patients to protection from unwarranted disclosure of medical or psychological information. While English common law does not recognize the tort of "invasion of privacy," it has "become established in virtually all states." An exception to the confidentiality rule has been assumed for "health-care providers and students who have a legitimate reason for access to private, patient-care data."

American society does not understand details of the means of transmission of AIDS and has a consequent fear of its contagion. This fear, coupled with hostility toward the high-risk groups who have developed AIDS, has led to serious concern that disclosure of a person's AIDS/HIV status could result in adverse actions for AIDS/HIV-positive persons in regard to employment, insurance, housing, and access to health care. Because information about an individual's HIV/AIDS status is particularly sensitive, disclosures of HIV-related information have been subject to an application of principles of tort law similar to that exercised in other cases of unauthorized release of a person's medical records. Enacted laws protect individuals from release of their HIV test results, but in exceptional situations these disclosures can be immune from liability. Obade notes that about 38 states and the District of Columbia have a statutory or regulatory system for insuring confidentiality of AIDS/HIV information.

The *Privacy Journal*, an independent monthly on "privacy in a computer age," publishes an annual compilation of state and federal regulations about privacy and requirements for disclosure when it is in the public interest (Smith 1992). Most states consider as reportable sexually transmitted diseases (STDs), tuberculosis, and child abuse; they allow varying

degrees of use of the information and offer a range of caveats about protection of individual identity. In *Estate of Urbaniak v. Newton* (1991), the California Court of Appeals ruled that "a health-care provider could be liable for invasion of the right to privacy . . . for improper disclosure of HIV-related information." The Superior Court of New Jersey, Law Division, ruled in April 1991 in a situation of "hospital gossip" about a patient diagnosed with AIDS that an "institutional provider [must] take affirmative steps to thwart the potentially damaging effects of the hospital 'grapevine'" (*Bebringer v. Medical Center of Princeton* 1991). It is noteworthy that in the United States, ethical decisions frequently are written into law or decided by the courts rather than determined in the medical arena. The abdication of responsibility in this area may reflect health care professionals' discomfort with a perceived lack of clarity about ethical issues.

In "Confidentiality, Disclosure, and Fiduciary Responsibility," J. F. Keenan holds that "the responsibilities entrusted to particular professions contribute to the determination of whether release of information is considered right and proper." He applies this insight to two groups of professionals: the news media, whose purpose is to provide to society information in the public domain; and the caring professions, specifically ministers, physicians, and psychotherapists, whose specific obligation is to protect the confidences they receive from people in their care. Applying virtue ethics to these four professions, Keenan identifies three guiding virtues for determining exceptions to the general obligations of confidentiality: prudence, fidelity, and justice.

Concerning the caring professions, he notes that the courts have generally ruled that they have an obligation to uphold confidential agreements as an important societal norm. He mentions a special section of seven articles in the journal *Society* (January–February 1992), in which several psychologists, psychiatrists, and social scientists discuss Dr. Martin Orne's release of records from his eight years of psychiatric counseling of the poet Anne Sexton. Keenan believes that in spite of speculation that Sexton would have granted Orne permission to release confidential records, Orne should not have done so. For Keenan, the therapist's duty to protect confiden-

tiality is based on the social nature of the profession rather than on an individual client's consent or request. Training, licensure, and peer recognition bind a professional to maintain confidentiality. The release of confidential information obtained in psychotherapy is a violation of the psychiatrist-patient relationship. Particularly it is unacceptable to release such records for publication in a trade book.

The obligations of clergy to respect confidentiality are similar to those of psychotherapists. Keenan states, however, that ministers need to recognize that there can be exceptions to the obligation of confidentiality even in "faithful relationship." Exceptions are possible on grounds of justice, he believes, as when the welfare of other persons is at risk. The "paradigm for upholding faithful relationships" (that is, for "maintaining confidences received during confession and spiritual direction") is less valid currently, especially in the midst of revelations about child abuse and sexual abuse.

Keenan's comments about confidentiality in medicine emphasize that fidelity makes a serious claim upon the physician, that confidentiality with family members cannot undermine the relationship between physician and patient, and that professional confidentiality is rooted in that "virtuous relationship." He discusses the patient's "right to know" and "right not to know," in cases of genetic disorders where information on carriers is available. Keenan raises questions about the physician's obligation to inform relatives who might be carriers of the relevant genetic disorders, but he does not provide an opinion about resolution of these dilemmas. Addressing the question whether the duty to protect a stranger from harm overrides the obligation to protect confidentiality with a patient who has AIDS, Keenan observes

that many people with AIDS are already reluctant to contact a physician and that "overriding confidentiality will not . . . promote the common good. Prudence requires that physicians continue to find ways of helping patients inform those who are or may be in danger." Keenan concludes, "Applying the science of moral reasoning to cases of disclosure and confidentiality highlights both the need for prudence and the role of fidelity and justice in guiding us to right conclusions."

These three articles and the available literature emphasize the significant dilemma for health care professionals, the clergy, and ethicists in trying to protect the rights of individuals to privacy and confidentiality in a covenantal relationship. The use of modern technology that provides rapid communication has attendant potential for abuse of privacy and confidentiality. Computer records, faxes, voice mail, and myriad innovative techniques allow dissemination of information about encounters with patients or parishioners that once was kept in the professional's handwritten or typed notes. In light of this potential for violation of privacy as well as the need for detailed historical background in order to treat patients or to counsel parishioners appropriately, the relevant societal agencies must find means to secure confidential data while allowing the appropriate professionals necessary access. Consideration of individual autonomy will need to be balanced against societal needs to evaluate burgeoning epidemics like AIDS, to conduct valid research, and to produce important data contributing to the improvement of society. The balance between respect for an individual's privacy and the right of society to be protected from real or potential danger has become a delicate one.

NOTE

1. See Rankin 1990 for an excellent analysis of confidentiality issues faced by clergy.

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What Makes an "Other"? Diversity, Disability, and the Softening of Our Hearts

Kathleen Nolan

Abby Lippman. 1992. "Mother Matters: A Fresh Look at Prenatal Genetic Testing." *Issues in Reproductive and Genetic Engineering* 5, no. 2: 141–54.

Susan Wendell. 1989. "Toward a Feminist Theory of Disability." *Hypatia* 4, no. 2 (Summer): 104–24.

William R. LaFleur. 1990. "Contestation and Consensus: The Morality of Abortion in Japan." *Philosophy East and West* 40, no. 4 (October): 529–42.

In the literature of religion and bioethics, new topics, perspectives, and forms of analysis are encouraged as a means to enrich and enliven discussion. Here—to

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some degree, at least—we assign a positive value to difference and diversity. Why is this so? What is it that determines the valence we apply to "otherness"? Why are difference and diversity valued in some contexts and ignored or viewed negatively in others?

These questions are rich both practically and theoretically, with their relevance extending to such diverse issues as rights of the disabled, care of the elderly, rehabilitation medicine, genetic screening and therapy, the moral status of animals, abortion, and environmental responsibility. Although seldom explicitly articulated, questions about the process and meaning of differentiation underlie many current bioethical dilemmas: conflict emerges both from the perceived need to establish boundaries and in subsequent disagreements about who will be excluded from or included in the established groups.

Differentiation—the creating of an other—can serve many purposes. Some forms of differentiation, for example, involve self-definition. When Abby Lippman proclaims that she will provide a "bold and impertinent" perspective on prenatal genetic testing, "sufficiently 'fresh' to be new" (p. 142), she seeks to separate herself from other authors writing about genetic testing. Lippman clearly sees a fresh approach as desirable *in its own right*, since she does not define

exactly what distinguishes her approach from others, or even what she is counting as the norm. Bypassing such possible ascriptions as *feminist*, *phenomenological*, or *narrative-based*, she defines herself as simply *other*. While it may be that this non-self-referential quality is itself one of the paper's "bold and impertinent" turns, it also seems likely that Lippman expects diversity of any kind to be appreciated; she relies on the fact that her ideas will be valued because they contribute something new and different.

Even self-differentiation, however, carries risks. This is implicit in Lippman's careful introduction of her critique of prevailing "stories" about genetic testing. These stories seem to present an objective account of illness and potential therapies but actually reflect the belief systems of the dominant group (in this context, health care professionals and policymakers), having been actively constructed to fit in with and reinforce prevailing norms. If Lippman rejects too many of these prevailing paradigms, she can become "other" with a negative valence, calling forth rejection and opprobrium. If she is too different, she will not be heard.

The risks involved in resolving this dilemma become painfully explicit in Susan Wendell's firsthand analysis of differences and disability. Disabled as an adult by a serious chronic illness, Wendell argues against using terms like *differently-abled* as a means to reduce the otherness of disabled people. Still, she recognizes the dangers of emphasizing difference from the able-bodied. For example, she hesitates to hold out acceptance of disability as a distinct and acceptable alternative way of living because this would directly challenge the value structure of the dominant group, which views itself as the paradigm of humanity.

Such challenges can trigger reflexive repression. As Wendell observes, if two groups begin with an unequal distribution of power, the consequences of imposing otherness are not entirely symmetric:

When we make people "other," we group them together as the objects of *our* experience instead of regarding them as fellow *subjects* of experience with whom we might identify. . . . Disabled people are "other" to able-bodied people, and . . . the consequences are socially, economically and psychologically oppressive to the disabled. . . . Able-bodied people may be "other" to disabled

people, but the consequences of this for the able-bodied are minor (most able-bodied people can afford not to notice it). (P. 116)

Nonetheless, the distancing and objectification necessary to the process of differentiation do hold serious consequences even for the dominant group, especially if any "distinguishing" features are shared by the supposedly separate groups. Wendell makes this point eloquently in referring to the "oppression of everyone's real body" inherent in the oppression of disabled people. By imposing "otherness" on disabled individuals, we maintain the illusion that only *they* are fallible: *we* have control over our bodies, *we* are free from weakness, illness, pain, and death. But the maintenance of this illusion comes at a heavy price: we become alienated from our real—imperfect and fragile—bodies, which we fear and cannot accept.

The effects of this alienation permeate our understandings of illness and medicine. Trying desperately to believe that "nothing this important is beyond our control" (p. 114), we fixate on possible psychological, moral, and spiritual causes of illness, accident, and disability, engendering guilt and self-doubt. Moreover, we create a system of medicine, and of medical ethics, that emphasizes surgery and high-tech interventions, further bolstering the illusion that someone can always "make it better."

Using the example of pain, Wendell explores the benefits of learning to accept limitations and to appreciate the important role that people with disabilities can play in educating the rest of society. Fear of pain and efforts to avoid it contribute to the spread of many social problems, including drug and alcohol addiction, and people with painful disabilities can teach us much about how they have faced what they can't avoid. Yet here a central ethical question emerges: assuming that we can and should become willing to accept limitations that are forced on us, or on others in society, how should we respond when we do in fact have some degree of choice? Should we abandon all pursuit of control?

Would there be anything wrong with using genetic diagnostic tests to avoid the birth of individuals with devastating illnesses or anomalies? With more minor conditions? Imagine that the test could be applied prior to conception, say on eggs and sperm, so that the issue of abortion could be circum-

vented: what harm would there be in preventing the conception of those who are "other" in ways deemed undesirable?

Some feminists and advocates of rights for the disabled have argued, and Lippman seems to imply, that such choices would be harmful to the interests of disabled people either because of the symbolism involved in the rejection or because a decrease in the percentage of disabled people in the population would likely lead to increased marginalization and discrimination against those present. Lippman also suggests that making such choices harms us socially by reinforcing our tendency to seek individual rather than collective solutions.

Yet why should any preventable disability be accepted simply because doing so would further these goals of feminists and advocates for the disabled? Surely we do not want to use future disabled individuals to serve even the most well-intentioned social agendas. Both Lippman and Wendell wrestle with this, and each suggests some helpful directions.

Trying to resist the framing of these questions in either/or terms, both Lippman and Wendell substitute questions that inquire into alternatives and priorities. For Lippman, this takes the form of "making mothers matter" through improvements in collective societal health, especially for women, rather than continuing to rely solely on "a DNA-based approach to personal and public health . . . that is fundamentally expensive, individualized, and eugenic" (p. 150). For Wendell, one of the most critical matters is the valuing of interdependence. Both insist that we need to go further in dealing with the real disjunctions that occur between individual desires and societal needs. As Lippman notes, "Disjunction exists because we have yet to develop ways for individuals and collectives to thrive and flourish simultaneously" (p. 151).

William R. LaFleur offers an intriguing path forward. Taking the relationship between individual choice and collective morality as his central focus, he describes a prototype of thriving social interaction, using as his surprising vehicle that most contentious of modern political dilemmas, legalized abortion. Noting an unexpected absence of rancorous public debates about the ethics of abortion in Japan, a country with both a high rate of abortion and a diversity of religious opinions on its morality, LaFleur employs a

detailed historical analysis of the evolution of Japanese ethics and culture to explain the emergence of this unexpected consensus.

LaFleur argues that a culture's ethical positions and insights can often be found within doctrines, rituals, and practices that fall outside the corpus of materials dealing specifically with ethics. These forms of indirect discourse reveal but do not impose moral positions; nor do they directly contest the views of others. As such, they capture important nuances of psychology and ethics while allowing for true diversity within the context of the good of the larger society.

In the specific case of abortion in Japan, LaFleur finds such a discourse in the rituals of memorial offered by traditional Japanese Buddhists for aborted fetuses. LaFleur interprets these memorials not only as attenuating the finality of abortion by creating a continuing relationship between the parents and an aborted fetus but, more important, as highlighting, in ritual form, the parents' grief.

Recognition of such grief is essential to prevent people from becoming inured to abortion—if abortion is necessary, then it is a "necessary sorrow," and people must guard against its generating a diminished sensitivity, or "hardening" of the heart (*kokoro*). Preventing the casual acceptance of abortion thus becomes more than an individual matter: "If too many people within society become persons who take abortion as simply a matter of course, then the tenor of society itself will change for the worse" (p. 537).

LaFleur obviously welcomes the introduction of arguments for abortion that take place outside the individualistic focus of the American prolife/prochoice debate. When he goes on, however, to argue in favor of a voluntary social eugenics, his conclusions extend far beyond the traditional attitudes revealed in the rituals of memorial and suggest the problems associated with adopting an exclusively societal focus.

LaFleur's conclusions seem a bit hard-hearted, if you will, in part because he boldly articulates what the culture had softened through ritual (that is, explicitly justifying abortions may make them not only "accepted" but also "welcomed" or "desired"). Yet the larger problem still seems to involve the "hardness" of rejecting an "other," whether a disabled fetus or an untimely pregnancy. It may be essential, especially in genetic decision making, to stay closely in touch with

this hardness—born of the pain of excluding potential “others” who are importantly also “ourselves.”

As Lippman points out, our current behaviors “selectively determine the culture in which our children will live” (p. 152). We therefore need to examine our values and decisions carefully, exposing

the egoism and intellectualism that can thwart our impulses to accept and even seek out genuine diversity. If we are to use genetic technology at all wisely, we must not lose sight of those feelings and discourses that can truly serve to soften our hearts.

NOTE

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NOTEBOOK

A Tennessee bill that would have allowed nurse practitioners broader authority to give patients prescriptions died in committee after some debate. Roscoe Dixon, the House committee chair, observed, "If you take the shackles off the nurse practitioners . . . you're



taking a gamble on whether or not they're going to continue working in underserved areas." The bill's sponsor, Representative Gary Odom, said, "I just think it's ludicrous to hold a profession hostage when the state is dealing with a severe lack of primary health care providers and the nurse practitioners can help to satisfy that need."

(*American Medical News*, 17 May 1993)



Terminally ill patients don't worry as much about dying as they do about how they will live until they die, according to Nessa Coyle, R.N., head of the supportive care program of the pain service of Memorial Sloan-Kettering Cancer Center. Coyle attributes much of the current mismanagement of pain to health professionals' repeatedly underestimating the severe levels of pain some patients experience.

"The concept of believing the patient as the expert on the level of his or her pain severity is critical to

appropriate pain management," says Coyle, and she suggests a variety of tools health professionals can use to assess the patient's pain. She points out that only 1 percent of all patients become psychologically addicted to pain control drugs. For the 20 percent of patients she believes have pain that can't be relieved using standard pharmacological and behavioral approaches, Coyle suggests consulting pain specialists at major cancer centers. For those few patients whose pain is unbearable, she suggests sedation to control symptoms, giving patients the option of being sleepy for a few days, followed by a period of being more awake.

For patients who discuss suicide, Coyle says, "it is important to assess suicide vulnerability factors, such as advanced illness, depression, hopelessness, pain, and delirium." Frequently those who commit suicide suffer from recurrent, underlying delirium, which removes people's inhibitions, freeing them to act on impulse. Delirium, she adds, "can easily be treated," and doing so "really makes other symptoms much more controllable."

Coyle believes doctors can and should honor patients' requests for pain control and suggests an "open, ongoing dialogue" with their caregivers. Asking them what they most fear and talking about what can be done will lessen their fears tremendously.

(*Hospital Ethics*, March/April 1993)



A study to examine the effect of insurance on the survival of HIV-infected patients suggests that patients infected with the HIV virus and dependent on government-funded insurance for health care have

higher mortality rates than those with private insurance. One of the researchers, epidemiologist Sana Loue, cautions that the study does not prove that the differential in mortality is related to access to care. She cautions, "There are probably numerous differences between the various groups that we were not able to measure due to lack of adequate data."

*(Journal of the American Medical Association,
9 June 1993)*



Colorado governor Roy Romer signed a bill in April 1993 that makes it a misdemeanor for demonstrators to come within eight feet of people entering or leaving abortion clinics.

(American Medical News, 17 May 1993)



In colonial times, the average age of the U.S. population was 16 years, and most people never reached old age. Since then, average life expectancy at birth has risen to 75 years, and now the elderly population of the United States is experiencing a growth spurt unprecedented in history. In 1990 the population group aged 65 years and older (with 31 million members) was ten times larger than in 1900 (with 3 million members). The aged in particular are living longer. From 1960 to 1990 the so-called oldest old population group—those 85 years of age and older—increased 232 percent (compared with a 39 percent increase in the total population), from 100,000 members to 3 million members. Between 1980 and 1990 the number of people over 100 years old grew 160 percent, from 14,000 to 36,000. According to the U.S. Census Bureau, it won't be long before more Americans will be of grandparenting age than will be young. In 1990, the number of people 60 and older nearly equaled the number of children under 14.

*(Journal of the American Medical Association,
12 May 1993)*



A recent Senate study found that only about 2 percent of rapists serve prison time, and victims continue to be treated with "suspicion rather than compassion."

The study, conducted by Democratic staff members of the Senate Judiciary Committee, also found that

- More than half of all rape prosecutions are dismissed before trial or result in acquittal. A rape case is twice as likely to be dismissed as a murder case.
- Nearly a quarter of convicted rapists never serve time in prison, and almost half of convicted rapists serve a year or less behind bars.
- A robber is 30 percent more likely to be convicted than a rapist.

The finding that only 2 percent of rape cases end in incarceration for the perpetrator was based on what the report called an "extremely conservative" estimate that more than 600,000 rapes are committed each year. Based on FBI statistics that 102,555 rapes were reported in 1990, the study estimated that at least 84 percent of all rapes are not reported; of those reported, no attacker was arrested 62 percent of the time; and when someone was arrested, the case was dismissed 48 percent of the time.

(Chicago Tribune, 5 May 1993)



Nearly half of America's 105 million families have an immediate member who lacks health insurance or



whose insurance will fail to cover large medical bills, according to a recent study by Families USA.

(American Hospital Association News, 12 April 1993)



Contrary to views that society isn't as religious as it used to be, a recent survey of 13 predominantly Judeo-Christian countries has shown that a majority of people still believe in God and an afterlife. Measured in terms of belief in God, heaven, and an afterlife, and in terms of weekly prayer and regular church attend-

ance two or three times a month, the most religious countries were the U.S, Ireland, Poland, and Italy; the least religious nations in the survey were the Netherlands and the former socialist nations of East Germany, Hungary, and Slovenia. Only the Netherlands



and the former East Germany did not have a substantial majority that believe in God (50 percent and 26 percent believers, respectively).

The majority of people in nine countries believe in life after death, with figures ranging from 80 percent in Ireland and 78 percent in the U.S. to 42 percent in Israel, 26 percent in Hungary, and 12 percent in eastern Germany. Belief that God "cares" about people varies widely: the numbers are high in Ireland, Poland, Italy, and the U.S., but only 26 percent in Slovenia, 19 percent in Israel, and 14 percent in eastern Germany.

The survey also found that despite widespread religious belief, a majority of Jews and Christians reject prohibitions against premarital sex and abortion.

(Chicago Tribune, 18 May 1993)



Three-fourths of long-term caregivers in the home are women, a third are in poor health, 8 out of 10 spend at least four hours a day providing care, and 35 percent who take care of elderly people are themselves over 65 years old (as reported by the 1990 U.S. Bipartisan Commission on Comprehensive Health Care).

*(Journal of the American Medical Association,
19 May 1993)*



"There has been a persistent effort by many health system analysts over the past decade to frame a 370-year-old African-American health deficit in nonracial

terms. Cancer offers excellent examples of this phenomenon. By using methodologies that are atomistic, individualistic, and reductionist in nature, recent studies ignore the adverse effects of many factors on the African-American cancer experience. Some studies downplay such major factors as structural inequalities in the American health system, and institutional racism in the health delivery, biotechnology, and health education infrastructures. . . . Other reports frame poor health outcomes, including cancer, in racially neutral terms, citing socioeconomic status (SES) and using language such as 'disadvantaged' patients and 'minorities,' which often understates the importance of race. When influential organizations such as the National Research Council, the National Academy of Sciences, and the National Institute of Medicine issue reports with perspectives which downplay race and emphasize SES, they convey the impression that race and racism are no longer problems in the American health system.

"Racism has influenced virtually every aspect of African-American life, including health. Cancer is no exception. Racism affected the health care and cancer outcome of black slaves. It continues to be a major contributor to the disparate health outcomes between African-Americans and whites in the U.S. Race prejudice has affected how cancer research and treatment resources have been utilized and distributed in America. Racism has helped to create a medical-social climate wherein black cancer victims are virtually blamed for their disease. Thus, there is greater emphasis on the 'culture of poverty' and on changing African-American lifestyles than on changing the health system toward providing equitable methods of cancer prevention, screening, early detection, and treatment."

*(Journal of Health Care for the Poor
and Underserved 4, no. 2, 1993)*



The Well Spouse Foundation is a national network of spouses of the chronically ill. Local support groups give emotional help to spouses at meetings, and the national group advocates programs like national long-term-care coverage and respite and home health care to ease the financial and emotional strain on the spouses and families. The foundation estimates that

7–9 million spouses provide much of the long-term care given in this country.

(Journal of the American Medical Association, 19 May 1993)



Each year, 2–4 million women are victims of domestic violence in the United States, meaning that more women are injured by domestic beatings than by car accidents, muggings, and rapes combined. Says Esta Soler of the Family Violence Prevention Fund, “The level of violence is so extraordinary that it is the single largest cause of injury to women.”

(Chicago Tribune, 2 May 1993)



AIDS is the leading killer among men 25–44 years old in 38 percent of U.S. cities of more than 100,000 people. Researchers at the Centers for Disease Control and Prevention said they had expected to find New York, San Francisco, and Newark on the list (with 35,



61, and 45 percent of deaths related to AIDS, respectively) but were surprised by the statistics in Salt Lake City (18 percent) and Macon, Georgia (19 percent). Also on the list were Los Angeles, 31 percent; Fort Lauderdale, 51 percent; Chicago, 16 percent; Dallas, 34 percent; Seattle, 39 percent; and Grand Rapids, Michigan, 17 percent.

(New York Times, 16 June 1993)



Most Americans believe in limiting futile medical treatment at the end of life, but only 5 to 10 percent have elected to use advance directives, living wills, or health care proxy documents. Sixteen percent (\$32 billion) of the Medicare annual budget is reimbursed in the last 60 days of life. Additional billions are paid

out-of-pocket, out of savings, and by private insurers. Bioethics consultant Joseph C. d’Oronzio suggests that registrants for Medicare, Medicaid, and Social Security benefits be required to complete advance directives. He notes that the choice to limit futile end-of-life interventions is also an economic one: “by limiting these unusually expensive activities, health care resources are conserved and perhaps can be re-allocated.”

(New York Times, 8 June 1993)



“Employed mothers face a fundamental dilemma. It is a pervasive societal assumption that it is in the best interest of the child to be cared for within their families, primarily by the mother, during early infancy, if not longer. Simultaneously, economic realities demand that women need to provide a share of the family income and have access to health care benefits



to provide for their children’s well-being. The dilemma is further compounded by the assumption that in order for women to gain equality with men, they must participate in work in the same way men do, with little accommodation to the demands of family life. This assumption seems to provide the basis for social and workplace policies that restrict time away from work and options such as flexible work schedules or childcare located near the worksite. All too often, commitment to work (and therefore job security and advancement) is defined as the ability to put all other life activities aside. In this environment, coupled with the limited availability of high-quality care and affordable childcare, children become a barrier to women’s equal participation in society. . . . Workplace policies and options are even more restrictive for women who are single, less well educated, or employed in traditionally blue collar occupations.”

(Nursing Outlook, March/April 1993)

Adina Blady Szwajger, the Warsaw ghetto doctor who poisoned her young patients as the Nazis arrived to seize them, survived the Holocaust and recently wrote a personal account of the episode. She was not driven by her own fear or dread, she says, but by the fear and dread of the children, who pleaded that she stay with them "until the end." She decided that she could best fulfill this pledge by becoming the agent of that end. She tells how she took two large containers of morphine and proceeded:

I took the morphine upstairs. Dr. Margolis [head of the tuberculosis ward] was there and I told her what I wanted to do. So we took a spoon and went to the infants' room. And just as, during those two years of real work in the hospital, I had bent down over the little beds, so now I poured this last medicine down those tiny mouths. Only Dr. Margolis was with me. And downstairs there was screaming because the Szaulis [units of Lithuanian collaborators] and the Germans were already there, taking the sick from the wards to the cattle trucks.

After that we went in to the older children and told them that this medicine was going to make their pain disappear. They believed us and drank the required amount from the glass. And then I told them to undress, get into bed and sleep. So they lay down and after a few minutes—I don't know how many—but the next time I went into that room, they were asleep. And then I don't know what happened after that.

Dr. Szwajger managed to escape from the ghetto and live with false papers for two years as a courier for the Jewish Fighting Organization. After the war, she devoted her career to pediatrics, specializing in tuberculosis in children. "But somewhere underneath," she admits, "I thought that I had no right to carry out my profession. After all, one does not start one's work as a doctor by leading people not to life but to death." She knows there were reasons for her behavior during that time, but memory cannot appease such knowledge.

(*Tikkun*, May/June 1993)

The fledgling "senior environmental movement" is an effort to study and draw attention to the effects of long-term exposure to environmental hazards on older adults. Environmental hazards under examination include lead, methanol in gas, pesticides, secondhand cigarette smoke, and radon. Responding to a Chicago official who said people would have to drink half a gallon of tap water a day for 70 years to suffer effects from elevated lead levels in the drinking supply, Joann Schwartzberg of the AMA Department of Geriatric Health said, "We've got an awful lot of 70-year-olds who have been doing just that. What risks are they facing?"

Lead has been related to high blood pressure and cardiovascular disease, kidney problems, iron deficiency, and chronic memory loss. At age 65, erosion of



bone mass begins to occur, particularly in women, releasing lead that the body stores in the bones into the bloodstream. Experts suspect this "leaching process" may be at the root of many age-related ailments.

Another indoor pollutant is radon, produced from radioactive decay occurring naturally in certain soils. The Environmental Protection Agency estimates that about 15,000 deaths per year can be traced to radon exposure. Other potentially hazardous indoor substances include carbon monoxide from gas stoves, formaldehyde from carpets, drapery, paneling, or insulation; and volatile organic compounds from paints, polishes, aerosols, sprays, or air fresheners.

Doctors say that the elderly are at particular risk from pollution not only because of long-term exposure but also because of the gradual wearing down of the immune system over time.

(*American Medical News*, 19 April 1993)

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The Florida Medical Association and Florida Bar Association have set up a toll-free telephone number through which Floridians can obtain a one-page living will form. Under Florida law, people can write their own living will to prevent life-prolonging treatment if there is no probability of recovery. People can also



appoint "health care surrogates" to make their decisions if they become incapable of doing so. The forms must be signed and witnessed but need not be notarized, and advice from attorneys and doctors is not needed.

Florida Bar president Alan Dimond said completing a living will preserves dignity, curtails unnecessary expenses, and is "a loving gesture for the loved ones who ordinarily would be left with weighty decisions and without the guidance of the person most intimately involved—the critically ill or dying person."

(American Medical News, 17 May 1993)

■

At workshops sponsored by the National Abortion Federation, abortion providers are given the opportunity to express their conflicting feelings as they seek to balance the rights and needs of patients with the reality of terminating pregnancies. "We're not ambivalent about the need for safe, legal abortion," says Terri Beresford, who trains counselors for planned

parenthood. "But abortion is not a simple-minded decision. It is a complex one. Everybody has mixed feelings."

Topics at the workshops include providers' feelings about women who come in for repeat abortions, women whose reasons for having abortions aren't ones they consider valid, feelings of anger toward women who wait until late in their pregnancies to have elective abortions, and feelings providers have toward the fetus, especially as gestational age increases. Many of the issues that disturb providers are the same ones that trouble abortion opponents.

"When I can identify the four chambers of the heart," said a physician assistant from New York who does ultrasounds to determine gestational age of fetuses in women with advanced pregnancies, "I start feeling miserable. And when I put my hands on somebody to feel how big they are and I get kicked, I'm barely able to talk at that minute. I want to say so badly: 'Why weren't you here six weeks ago?'" Other providers expressed difficulty in counseling patients who want to have an abortion because they are carrying a girl and wanted a boy.

"Even though we say 'No woman should have to justify her abortion,'" Beresford says, "in your heart you know that you are more sympathetic at this time in your life to certain reasons than you are to certain others. And it changes for us over time."

An Arizona clinic administrator said, "One of the things that we've done is talked about where does the soul go." It helps when the staff can sit down and say things like "That's what disturbed me about seeing that little face. I know I'm not going to burn in hell anymore. But I'm still kind of concerned about how it all fits together."

Says Terri Beresford, "Everybody in the world is ambivalent about abortion. Abortion is about life, death, and sex. And except for eating, that's everything that matters to us. So it's no wonder we've got issues."

(American Medical News, 12 July 1993)

BOOKS

Mind and Body, but Spirit Too

Arthur W. Frank

Bill Moyers. *Healing and the Mind*. New York: Doubleday, 1993.

HEALING AND THE MIND, both the five-hour PBS series shown in February 1993 and the book, will certainly enhance Bill Moyers's preeminence as a public educator. Together the book and the series should affect therapeutic and policy agendas for years. Effective use of two media resulted in a complementarity of book and video, and those who have seen the series should not feel they have already "done" the book. One of the 15 interviews was not in the series at all, other interviews expand what was shown on video, and Moyers's five editorial introductions appear only in the book.

The book's most distinctive feature is not its additional text but the illustrations. Rather than use stills from the videos, art editor Elizabeth Meryman-Brunner has assembled a mostly modern collection that challenges how we perceive perception. The pictures cast us back to the book's fundamental question, What is "the mind," and what are the limits of its powers? The illustrations highlight the element of mystery that can become secondary in the interviews.

The sequence of the interviews in the book and the series also differs. The book's movement is from the outside inward, and from the material to the

spiritual. Moyers begins with environmental effects on health. These issues deserve to be underscored, even if we have been told before that more money is spent on health and less satisfaction results (p. 33), that much application of technology is "mindless" (p. 38), and that stress affects health (p. 50). Moyers moves equally slowly when he then discusses behavioral therapies using biofeedback and conditioning; he aspires to reach a general audience and is laying a careful foundation.

We go from behaviorist intervention to conscious life-style modification as Moyers interviews Dean Ornish, Jon Kabat-Zinn, and David Spiegel. Ornish's cardiology research shows that a regimen combining diet, meditation, and group discussion bordering on therapy can reverse arterial blockage. In controlled studies the life-style modification group is doing better than a matched sample receiving standard drug and surgical interventions. Kabat-Zinn uses modified Buddhist meditation and yoga to treat patients who have exhausted other medical help; his follow-up studies are also impressive. Spiegel is now replicating his earlier study of women with metastatic breast cancer. Those in a loosely structured support group showed significantly longer remission periods than a matched sample not in the group. Like the section on environmental effects, this work is fairly well known, but Moyers's presentation gives it added depth, as in Ornish's description of how his personal history led him to his current practice.

So far we have moved from recognizing the effect of the social environment to changing how the individual deals with stress and makes life-style choices. We then leave the sphere of conscious mind;

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biochemistry dominates the next interviews. To this point the book has provided a case for medical reform and expansion of services. The interviews on biochemistry suggest a more radical critique of what the medical model of the last several hundred years has excluded from therapeutic consideration.

Candace Pert, a biochemist, finally (we're halfway through the book by now) provides a working definition of *mind* as "some kind of enlivening energy in the information realm throughout the brain and body that enables the cells to talk to each other, and the outside to talk to the whole organism" (p. 189). This "conversation" is not, however, subject to conscious manipulation. Moyers asks Pert the question that popularized "mind-body cures" hinge on: "will we ever be able to put our minds and our bodies in a certain state so that we can affect our immune system positively?" (p. 190). Her answer, like the other answers to various forms of this question throughout the book, is a theoretical yes but a practical no, not at the present time.

Pert recognizes the problem that false promises can bring, most specifically, guilt. "If it's true that emotions are critical in health and disease, then people shouldn't feel guilt, they should just start to take in this new information. People need to open up and learn not to feel guilty but to learn new ways of being and thinking, new therapies, and new strategies" (p. 192). This "opening up" may be easier said than done. What a demand it is on people who are not recovering from cancer to tell them that their emotions affect their nonrecovery but that they shouldn't feel guilty about it. In the long run Pert is certainly right. Guilt is a serious problem, but shying away from possible therapies is no response to that problem.

The challenge to medical practice becomes most explicit in the interview with physician and neurobiologist David Felton. Felton's research showed the presence of nerve fibers in the immune system, a finding that went against previous medical dogma that the immune system was autonomous. The presence of nerves suggests that the mind is implicated in the immune system, taking us back to Moyers's question to Pert: can we consciously affect our immune systems? Felton's answer to that question, like Pert's, is highly qualified. His opinion about how medical practice should change is more conclusive. His findings mean that "we have to pay very

close attention to the feelings and perceptions of patients, and *how they view* their health, their disease, and the status of their illness" (p. 216; emphases added).

Felton's statements on the issue of how medical treatment is delivered are among the most revolutionary in the book:

For example, studies suggest that a patient who can look out the window during recovery from some specific type of surgery stays there a shorter time than the patient who can't look out a window. The environmental circumstances of the hospital make a difference in how well a patient recovers. There's a lot of literature on that, although basically it's been ignored, because for many decades we've practiced medicine more for the benefit of the staff and the hospital than for the benefit of the patients. And that is something that has to be changed. We have to start looking at the impact of the environment on how a patient recovers. (P. 233)

Earlier interviews have made similar statements but not on the basis of findings in biochemistry and neuroscience. What we call the "medical model" justifies a whole organization of hospitals and other services, and this model has been based on disease as a closed system inside the ill person. The physician intervenes not as one person affecting another person but as an impersonal agent administering drugs or surgery; these are what affect the disease. The only thing that counts is the effect of this intervention on the disease. The patient's perception of the treatment milieu, including the patient's relationship to the doctor(s), is regarded as incidental—a matter of "amenities."

In an earlier interview on social conditions of treatment a physician says the issue is not amenities but empowerment (p. 33). Felton completes the circle by suggesting that empowerment is not only social but physiological. Whether the medical system is perceived as humane and ethical affects whether it achieves maximum cure according to the most rigorous "scientific" criteria. How people *perceive themselves* being treated may count as much or more than that treatment itself because "perception" is not just in the brain but in the immune system.

Where does Moyers go with such revolutionary

ideas? The simple answer is China. The book's next section deals with *chi* (or *qi*), the Chinese concept of "vital energy," and the medical treatments such as acupuncture that follow from understanding the body based on the flows and blockages of *chi*. The material in these chapters is nicely packaged, but why go to China? There are extensive practices of nonallopathic medicine in North America, so why not stay at home?

Here we reach a central limitation of *Healing and the Mind*, a limitation that is fully self-conscious and defensible. Moyers writes that his inspiration for the series came from Norman Cousins's infectious commitment to spreading the news about the healing power of the mind. When Moyers finally proposed the series, a colleague wrote that he should not produce it because the message might lead some ill person to drop out of medical treatment. "Her warning registered," Moyers writes; "the 'Heal thyself!' message so implicit in some popular books promises more self-deception than self-healing" (p. xiii). Thus when Moyers does present nonallopathic therapies, he places them as far away as possible and underscores their embeddedness in Chinese culture. I couldn't avoid hearing a message of "Don't try this at home."

I respect Moyers's caution and agree with his characterization of the "self-deception" of many popular books. Still, the very excellence of this series sets an agenda, and what is left out of that agenda will take that much longer to bring back in. Both the television series and the book convey a strong message that whatever the future is, institutional medicine will provide it. This premise should not go unquestioned.

In the book Moyers has chosen to privilege the voices of professional medicine exclusively: all the interviews are of physicians and research scientists working in medical settings. They continue to view mind and body as a biochemical circuit but allow that environmental stresses influence that circuit. In making that allowance they demonstrate a more expansive view of disease than many physicians have, but the possibility remains unexplored that the biochemical circuit is susceptible to influences outside current medical conceptions of what can influence this circuit.¹

These criticisms do not disappear after the final interviews, but the power of the total project does diminish them. Moyers goes to Commonweal, a California therapy and research center, and films can-

cer patients who spend a week together learning to live with cancer. Commonweal offers no medical or adjunctive therapy and specifies that everyone there is under medical supervision. The question Commonweal invites people with cancer to pose for themselves is stated by their president, Michael Lerner: "How do you want to live? How do you want to be in this period of your life?" (p. 339). Commonweal offers rest, diet, and meditation, but mostly it offers an opportunity to speak. Naomi Remen, medical director, says, "I think the greatest thing you can ever give someone else is your attention—not with judgment, but just listening" (p. 345).

As inspiring as the interviews with Lerner and Remen are, they need to be read along with the final video segment. Moyers removes himself from most of this program and shows a group of participants in a Commonweal retreat speaking of their lives with cancer. We see the effect that being listened to has on them. Seldom have the critically ill been given such voices, and seldom has the effect of finding a voice been so visible.

Naomi Remen talks about her own illnesses and how she has learned to live with them. "I'm not sure I have gotten rid of my loneliness," she says. "I've just invited a lot of people into it, to be there with me" (p. 346). This is the essence of Commonweal: to give each an opportunity to invite others into his or her loneliness. That invitation also underscores the power of Jon Kabat-Zinn's meditation group, David Spiegel's group for women with advanced breast cancer, and Dean Ornish's cardiac rehabilitation retreats. These mutual discoveries of our voices may be as far as we can presently go toward David Felton's invocation of the importance of the ill person's perception of treatment.

Moyers, at least in his journalistic persona, wants to go further. His exchange with Remen (edited from what is seen on film) takes the healing enterprise through a final turn:

Moyers: But isn't the best thing a doctor can do for people who are ill is fix them?

Remen: If it's possible, yes. We all want somebody to take away our pain. But there are limits to what technology can do. And not everything is fixable.

Moyers: But what about your own experience? The surgery fixed you.

Remen: No, *it just gave me another set of problems to live with.* We don't fix the people who come here, we simply offer them an experience which allows them to explore who they are as human beings and get in touch with strengths they didn't know they had, and to see themselves and their lives differently. (Pp. 346–47; emphases added)

Remen's statement that her own surgery "just gave me another set of problems to live with" is an essential counterbalance to much of the rest of the book. Ideas of God and the soul are a constant subtext of *Healing and the Mind*, though they are never explicitly developed. Dean Ornish and Candace Pert both suggest how their work has led them toward the spiritual. Ornish's work leaves him feeling "as if we were part of something larger than ourselves" (p. 105); Pert's research recognizes that "there's a form of energy that appears to leave the body when the body dies" (p. 182). Moyers chooses to respond to these openings with a voice of science and rationalism, just as he responds above to Remen.

In his role of public educator Moyers adopts an interview persona that excludes nontechnological responses to illness. This persona becomes a materialist straight man during a short, funny, and profound segment with a Chinese *t'ai chi* grand master, Ma Yeuh Liang, who—we also learn—was trained in Western science and ran a hospital laboratory. Master Ma tells Moyers it took him 10 years to discover his *chi* (vital energy) and 30 years "to learn how to use it" for healing. "Do you think Westerners can ever get this?" Moyers asks, adding with undetectable irony, "We want our payoff now."

Master Ma's response is elegant in its simplicity: "You must change your manner" (p. 288).

What a change of manner Naomi Remen proposes when she tells Moyers that surgery did not fix anything but only gave her "another set of problems to live with." The spiritual challenge of *Healing and the Mind* is not just Pert's intimation of an energy we could call soul or Ornish's perception of being part of something larger we could call God. I choose to meditate most on Naomi Remen's gentle invitation to live life, gratefully, as a progression of problems, each leading only to the next. Near the end of her interview she says:

My sense is that all power comes out of the ability to accept what is. Acceptance is what allows change. Accepting that one has cancer is the first step to healing yourself. . . . Maybe you won't be cured of cancer, but you won't lose your life—and it's easy to lose your life these days. Seeking physical healing is important, but it may not be the ultimately important thing, at least not for me. (P. 361)

The danger of high-tech medical interventions is that because they offer so much, they can seduce us with the wrong payoff. As Remen reminds Moyers, the spiritual challenge of illness is that "it's easy to lose your life these days."

The page following this quotation has, as the last illustration in the book, Henri Matisse's *Dance* showing five nude figures joining hands in a circle that seems to move, even on the page. *Healing and the Mind* tells us a great deal about physical healing, but its final gift may be to remind us of the ultimate importance of accepting our place in the dance.

NOTE

1. See, for example, Larry Dossey's *Meaning and Medicine* (New York: Bantam, 1991) for discussion of studies of healing that takes place without the ill person's knowledge that it is being attempted. Fred Frohock's *Healing Powers* (Chicago: University of Chicago Press, 1992) contains similar material, which, if anecdotal, is compelling. Dossey's next book, *Healing Words* (San Francisco: Harper San Francisco, forthcoming), reviews the many scientific studies of the healing efficacy of prayer. In these studies Western medicine approaches what Buddhists would call "big Mind," a transcendental linkage of persons outside the biochemical circuit of bodies but nevertheless capable of affecting individual bodies.

BOOK NOTES

Robert F. Murphy, *The Body Silent* (New York: Henry Holt, 1987), 242 pp.

IN THE PROLOGUE OF *The Body Silent*, Robert Murphy declares his purpose: to present "the social history of a paralytic illness that has taken me slowly and inexorably from its first symptom, a little muscle spasm in 1972, to quadriplegia in 1986, the year in which these words are being written" (p. 3). His account of the impact of a slowly growing tumor in his spinal column details both the physical and the social adaptations forced upon him by his condition.

The period of diagnosis and initial treatment gives Murphy, a cultural anthropologist who has enjoyed excellent health for 48 years, a chance to experience patienthood firsthand. He speaks matter-of-factly but tellingly of the indignities and realities of hospital life, with its unique internal schedule and its unspoken rules on how to be a "successful sick person" (p. 20). As his impairment worsens, he encounters physical obstacles but also the social obstacles that isolate the disabled and damage their identity in large and small ways. Examples from Murphy's own experience, his contact with others who are disabled, and his reading support his conclusions about the most far-reaching changes in the consciousness of the disabled: "lowered self-esteem; the invasion and occupation of thought by physical deficits; a strong undercurrent of anger; and the acquisition of a new, total, and undesirable identity" (p. 108).

Murphy documents the gradual diminishment of his physical abilities and conveys powerfully the importance of each degree of autonomy lost. (At one point, for example, he speaks of being able to brush his own teeth, using a toothbrush with a special thick handle, but not being able to squeeze the toothpaste tube because his grip is not strong enough.) For Murphy the thickest line can be drawn between his pre-wheelchair and post-wheelchair days, but even the small steps of decline have drastic importance: as his arm strength deteriorates, an eighth-inch in the height of a door sill comes to mean the difference between being able to move his wheelchair from one room to another or having to wait for someone else to push him.

Such ever-increasing dependency, Murphy shows, "invades and erodes the very compact upon which association between adults is premised" (p. 199). He chronicles in careful and convincing detail the alterations wrought by his changing physical status upon his relationships with friends, students, colleagues, and family members. He notes the curious social leveling that takes place as his impairment becomes more obvious: Gender, class, and racial differences assume less importance—women on elevators now begin conversations with him; black campus policemen to whom he was formerly invisible now greet him. A chapter on love and dependency gives particular attention to his relationship with his wife of 36 years.

In the final chapter ("There's No Cure for Life"), Murphy develops the notion that his paralysis can be seen as an "enactment in exaggerated form of the course of all social life," "an allegory of life and entropy" (p. 222). People in this condition have a foretaste of what is to come for everyone, and thus they represent what others would prefer to avoid. But readers of *The Body Silent* dwell for a time within this inevitable movement toward entropy, and it is a perspective-altering experience.

—Barbara Hofmaier

Sharon R. Kaufman, *The Healer's Tale: Transforming Medicine and Culture* (Madison: University of Wisconsin Press, 1993), 354 pp.

"LIFE COURSE STUDIES" IS THE NAME given by the University of Wisconsin Press to the series in which this set of studies of life courses appears. The lives in question are those of seven physicians as they make their passages from childhoods early in this century through medical school in the 1920s and 1930s to seniority in our own day.

Sharon R. Kaufman, a medical anthropologist at the University of California—San Francisco, conceived the idea of addressing issues of medicine and culture by paying attention to a range of veteran physicians who were well regarded by colleagues if not necessarily celebrities. Her technique of interviewing has come to be known as the "Studs Terkel" approach, after the Chicagoan whose books (*Division Street*, *U.S.A.* and the like) allow ordinary people to talk. The

voice of the tape recorder and the personality of the transcriber are simply erased. So in the case of Kaufman's subjects, the reader has the impression of being in on sustained chats with sage people. At almost any moment, one thinks, the interviewee would patiently listen for response.

Mention of the technique is relevant here because *The Healer's Tale* is anything but a set of didactic or apodictic declarations about how medicine transforms culture, and vice versa. Such literature is abundantly available, often scientifically appropriate, and, not seldom, eminently forgettable. After Kaufman has introduced her cast of six men and one woman from various parts of the nation and in various specialties (or general practice), they speak for themselves on a variety of subjects: "Becoming a Doctor: 1920s and 1930s"; "Specialization: 1930s"; "Generalists, Scientists, and Curers: 1930s and 1940s"; and "Power and Influence: 1946–1970s." Kaufman names 1945–65 a Golden Age, but fortunately the physicians, who naturally regret the loss of some of the personal ways of olden days, do not lapse into expressions of nostalgia or curmudgeonhood. They simply and wisely tell of their work and their environs in these decades and offer little suggestions about transformation along the way.

Dr. Jonathan Rhoads of Pennsylvania is here associated with a Quaker heritage and Quaker conscience. Dr. Saul Jarcho comments on a young physician who, not knowing the difference between a Scottish Presbyterian ("grim") Calvinist and an Irish Roman Catholic in respect to confession, counsel, and care, fails to grasp "the elementary relation between man, illness, and environment [as being] of great significance" (p. 246). Issues of religion and faith are not up front, but the physicians and the author exemplify a compelling high humanism and an instinct for care.

—Martin E. Marty

Alice Walker, *Possessing the Secret of Joy* (New York: Harcourt Brace Jovanovich, 1992), 286 pp.

ALICE WALKER HAS WRITTEN AN IMPORTANT BOOK on the topic of female genital mutilation—commonly miscalled "female circumcision." Other books have treated this subject, but none has secured the readership Walker's book is likely to. What is Walker

writing about? The "Womanews" section of the *Chicago Tribune* of July 18, 1993, carried Soraya Mire's story:

In my country [Somalia] the custom is for the clitoris, labia minora and majora to be cut off, and the remaining tissues are sewn together, leaving only a small opening for urine and menstrual blood. This is performed by a midwife . . . using no anesthetic, with non-sterile razor blades, scissors or pieces of cut glass. This is usually done to girls between ages 5 and 10 . . . The woman remains sewn shut until marriage.

I was like many girls in that I developed problems . . . The opening was not large enough and I had a bladder infection and retention of menstrual fluids. This caused a painful condition in which vaginal stones were formed. Some women develop massive scarring, which causes problems during childbirth. Double episiotomies are common. . . .

Mire does not mention that the practice may cause fatal hemorrhaging and that it also transmits AIDS, because the same cutting instrument is used on a number of children. She doesn't tell readers about the pain that attends vaginal intercourse or of difficulty with such daily activities as vigorous walking.

Walker's novel is the story of Tashi-Evelyn Johnson, an African-born woman who returns to her native country and undergoes circumcision as a way of embracing that which is distinctly African. By telling the story of Tashi's agony—both from her own mutilation and from the remembered death of her sister in childhood—Walker exposes what the hidden practice really is and the forces that fostered and perpetuate it. In linking its origins to the displacement of ancient goddesses by a male deity, Walker shows that what we worship has direct consequences in daily life—in this case on women's flesh.

Since genital mutilation has been misnamed *circumcision*, falsely implying that it is analogous to male circumcision, Walker describes what a comparable loss would be for a male. She shows that women participate in the victimization of their daughters, yet she puts this "collaboration" in perspective by depicting women so damaged that they are no longer able to protect their own children. "I used to think my mother thought about me. . . . In truth, my mother

was not equipped, there was not enough of her self left to her, to think about me. Or about my sister Dura, who bled to death after a botched circumcision, or about any of her other children" (p. 272).

Walker ties this diminution of women's power to the establishment of male-dominated faiths. Not only are these ancient beliefs implicated in the instigation of female genital mutilation, but Christianity is faulted also—for its silence. Tashi-Evelyn grows increasingly agitated as she sits in her pastor husband's congregation Sunday after Sunday.

I am a great lover of Jesus, and always have been. Still, I began to see how the constant focus on the suffering of Jesus alone excludes the suffering of others from one's view. . . . I knew I wanted my own suffering, the suffering of women and little girls, still cringing before the overpowering might and weapons of the torturers, to be the subject of a sermon. . . .

"One sermon, I begged him. . . ."

He said the congregation would be embarrassed. . . . (Pp. 273–74)

I hope this book will not be considered just a woman's book or a book too depressing to read. I hope that her book will bring about one thing necessary to end the practice, namely, an emphatic and unanimous moral condemnation of the practice, similar to the worldwide repudiation of apartheid in South Africa. It is odd, ironic, and disappointing that the dust jacket copy refers to female genital mutilation as "one of the most controversial issues of our time," thereby implying that thoughtful and humane people can occupy a range of positions on the issue. What about female genital mutilation is there to be "for"? And why?

When Tashi-Evelyn begins therapy with a white, male psychiatrist, she thinks to herself, "But how could I talk to this stranger of my lost children? And of how they were lost? One was left speechless by all such a person couldn't know" (p. 18). Alice Walker takes all of us who "couldn't know"—as whites or as Westerners or as males—and tries to make Tashi's experience real to us. Tashi cries out in the courtroom: "Can you bear to know what I have lost?" (p. 35). We have no excuse now for not knowing.

—Sandy Pittman

Patrick T. Hill and David Shirley, *A Good Death: Taking More Control at the End of Your Life* (New York: Addison-Wesley, 1992), 160 pp.

THE RECENT POPULARITY OF BOOKS ON DEATH AND dying indicates a shift in Americans' reluctance to confront end-of-life issues. A fear of protracted dying coupled with an awareness of the limits of medical treatment has created a vigorous debate about the right to die. The range of options and resources that have emerged from this debate can create a sense of helplessness and confusion on the part of the dying and their loved ones, along with great interest in these issues as people speak of wanting to gain some measure of control over their dying. Unlike the approach taken in recent books by Jack Kevorkian and Derek Humphry, *A Good Death* offers a balanced and informative discussion of various issues that concern people facing the end of life. The authors present a persuasive case that the institutionalization of death in American society requires serious reconsideration, that there is a need to reclaim the personal nature of the experience.

This short book summarizes current laws on end-of-life care, including how to write a living will and how to appoint a health care proxy. The authors present a candid discussion of the advantages and disadvantages of advanced directives, what to expect in intensive-care units, chronic-care hospitals, nursing homes, and hospices. These discussions include case studies and interviews, which also describe what it is like to be on a respirator and to receive artificial nutrition as well as the need for better pain management in caring for people at the end stages of life. In a concluding chapter, the authors review what a variety of the world's religious traditions say about termination of treatment and other right-to-die issues. Generally these reviews are constructed to show how a religious tradition can support a favorable position on a person's right to die. Certainly counterarguments could be made from within any of these traditions. Also, in the profile of Buddhist views of suicide and the natural way of dying, the authorities cited are Western converts or scholars, whose explanations are presented in the language of Western philosophy.

The authors' support of one's right to die is clear. This claim is not an indictment of the book's content or presentation; its review of the legal situation in the

U.S. is accurate, and its discussion of the steps required to develop a living will or durable power of attorney is good, especially in its review of the importance of talking with physicians, religious representatives, family, and friends. Any encouragement to break the usual silence about death and dying is welcome, yet arguments against a right to die will have to be found elsewhere. Still, *A Good Death* is a generally balanced and informative review of the personal and health care issues challenging patients, families, and caregivers who are facing end-of-life decisions.

—Edwin R. DuBose

William A. Galston, *Liberal Purposes: Goods, Virtues, and Diversity in the Liberal State* (Cambridge and New York: Cambridge University Press, 1991), 343 pp.

GALSTON, A POLITICAL THEORIST at the University of Maryland, has examined the disputes of the last 20 years in liberal politics and theory and endorsed a middle ground. Liberalism, he says, is not neutral and should not attempt neutrality as an alternative to endorsing a loose account of human good. On the other hand, liberalism should not be overwhelmingly partial to particular understandings of the good life. Liberalism, rather, should follow a *via media*, respecting liberal premises such as freedom and diversity while it supports a certain range of basic goods. He rejects the skepticism that disallows any consensus on the good, and he exposes the mistaken notion that neutrality (a liberalism without content) is possible; he argues instead that American liberal politics is and should be, within defined conditions, full of content and purpose. What liberal politics and liberal theory should be worried about, he contends, is not neutrality but the social practices and institutions that foster and ground liberal unity within diversity. Of particular concern to Galston is the relationship between liberal politics and religion.

Before laying out the supports for liberal unity and their justification, before approaching the religion question, Galston provides extensive rationales for rejecting an impossible liberal neutrality in favor of a limited, socially accepted consensus on social goods and evils. He maintains, against postmodern skeptics, that social critique is possible.

Just sentences before embarking on the second

half of the book, where he describes the conditions necessary for his non-neutral liberalism, Galston brings up a secondary theme—his concern that liberal politics, in its keen desire to build policies around a free and equal moral personality and in its efforts to help the least advantaged, left the American working class behind. The American working class, Galston warns, does not grasp and endorse liberalism because of its compelling philosophical tenets. They adopt liberal core commitments because they learn them as children and grow up in the liberal milieu. It is at this point, the transition from theory to practice, that Galston begins his outline of the necessary support structure for a liberal polity.

Civic virtues, says Galston, must respect individual diversity yet promote public spirit and sustain the wide tolerance that is so essential in liberal society. How does society go about inculcating a public spirit? Civic education teaches the virtues necessary for living in a widely cohesive liberal polity. Galston maintains that moral enculturation does not violate individual conscience because privacy of conscience can be protected only in a *civil* society. Parents may not impede (though there are careful exceptions to this) the teaching of liberal commitments and the formation of civic character. Galston believes that children must learn how to measure their society against others, that children must learn tolerance, but that this is quite “compatible with unswerving belief in the correctness of one’s own way of life.”

If civic education is one way of maintaining the support structure of modern American liberalism, religion is another. Until recently society accepted religion’s role in shaping individual moral conduct as a contribution to the social preconditions for the American liberal polity. But religion in this century came to be defined as Protestant mores, especially the moral expectations of white Anglo-Saxon males. The civil rights movement shattered this dominant ethos by exposing the chasm between the nation’s founding principles and its practice. Black leaders worked to legitimate social difference and refused to give up their cultural distinctiveness. Others followed their example, and traditional morals were further weakened by court decisions on school prayer, pornography, and abortion.

There are three ways of looking at this turn of events. Juridical liberals who favor civic neutrality

welcome this as a neutral zone for public morals. Traditionalists (religious fundamentalists by and large) see this as a secular humanist onslaught. Thoughtful liberal moderates, says Galston, see the need to preserve the delicate relationship between religion and liberal politics, because religion fosters liberal virtues, and a liberal politics protects and accommodates the free practice of religion. This latter group can be a mediating influence. They can make distinctions between disapproval, prohibition, and neutrality and find ways of preserving what is important to the two extremes. Hence Galston sees the moment-of-silence decision on school prayer as a principled resolution of a bitter dispute. He proposes that liberal moderates can suggest social policy with the

aim of sustaining intact, two-parent families while still protecting liberal freedoms.

Galston has written a very interesting book, with the most interesting proposals appearing in the last third of the volume. It is not likely that every political theorist will agree with his moderate, mediating, purposive, virtuous liberalism. His notion of liberal conservatism, preserving what is worth saving in a tradition or belief system while remaining true to liberal principles, may not pacify either juridical liberals or serious fundamentalists, but it may just be what the American working class would like to see more of. In the end, Galston has worked out a clearer definition of what the middle ground looks like in the American liberal polity.

—*Agnes Coveney*

LITERATURE DIGEST

Modern medicine and healing beliefs

David M. Eisenberg, Ronald C. Kessler, Cindy Foster, Frances E. Norlock, David R. Calkins, and Thomas L. Delbanco, "Unconventional Medicine in the United States," *New England Journal of Medicine* 328, no. 4 (28 January 1993): 246–52.

David J. Hufford, "Epistemologies in Religious Healing," *Journal of Medicine and Philosophy* 18 (1993): 175–94.

IN JANUARY, THE *New England Journal of Medicine* reported surprisingly high use of unconventional therapy in the U.S. The numbers tell the story: "in 1990, Americans made an estimated 425 million visits to providers of unconventional therapy. This number exceeds the number of visits to all U.S. primary care physicians (388 million). Expenditures associated with the use of unconventional therapy in 1990 amounted to approximately \$13.7 billion, three quarters of which (\$10.3 billion) was paid out of pocket. This figure is comparable to the \$12.8 billion spent out of pocket annually for all hospitalizations in the United States" (p. 246). Unconventional therapy was characterized as "medical practices that are not in conformity with the standards of the medical community" (p. 246). These practices include relaxation techniques, chiropractic, massage, imagery, spiritual healing, commercial weight-loss programs, life-style diets (for example, macrobiotics), herbal medicine, megavitamin therapy, self-help groups, energy healing, biofeedback, hypnosis, acupuncture, folk

remedies, exercise, and prayer. Among these, prayer and exercise were the most frequently reported, by 25 and 26 percent of patients, respectively. Unconventional therapy was generally sought for chronic medical conditions rather than life-threatening ones, and most patients who used unconventional therapies (83 percent) also sought treatment from a physician. To dash quickly any resort to stereotypes, however, the authors give demographic analysis as well: "One in three respondents (34 percent) reported using at least one unconventional therapy [excluding exercise and prayer] in the past year. . . . The frequency of use of unconventional therapy varied somewhat among sociodemographic groups, with the highest use reported by nonblack persons from 25 to 49 years of age who had relatively more education and higher incomes" (p. 246).

This last piece of data is the starting point for David Hufford's article "Epistemologies in Religious Healing." Why are unconventional healing practices so widely accepted and employed by well-educated and affluent members of modern society, individuals well-schooled in the canon of scientific rationality? As Hufford notes, "If these beliefs and practices were found primarily among people unfamiliar with modern thought and the achievements of scientific medicine, they might be discounted as resulting from an unreflecting acceptance of obsolete knowledge or naive and emotionally biased reasoning" (p. 175).

As Hufford indicates, "religious beliefs are central to the modern resurgence of nonorthodox healing" (p. 177). Thus what is often at issue here is a conflict between scientific claims to knowledge and agency and religious claims to knowledge and agency. Conventional scientific thinkers typically consider

religious belief (belief in the efficacy of a supernatural agent or element) to be incompatible with rational modern thought, explaining it away as nonrational thinking, "special logic," or psychological compartmentalization. Hufford argues that the persistence of belief in religious healing in the modern context is far from nonrational and that the actual beliefs of individuals are often rationally ordered and empirically founded.

Skeptics often charge that religious reasoning in a modern and well-educated person is an example of psychological compartmentalization, what philosopher Anthony Flew describes as "the ability to hold two contradictory beliefs simultaneously, accepting both of them" (p. 177). In this view, religious beliefs are like superstitions, "compartmentalized" so that they do not corrupt a practical rationality. Hufford, however, argues that neither the notion of special logic nor compartmentalization is "necessary in order to understand the religious healing beliefs of many modern individuals. Indeed, the thought processes by which they reason about healing are the same as those used in other matters. The difference between believers and nonbelievers has more to do with assumptions and criteria for evidence than anything distinctive in the reasoning used" (p. 177). Differences between believers and nonbelievers and between orthodox medical thinking and religious thinking arise from differing assumptions, different value given to subjective experience, and the particular experiences of believers.

Belief in religious healing conflicts not only with the canons of medical science but also with current canons of mainstream theology. Hufford notes that since the Enlightenment, Protestant theology especially has moved away from religious empiricism, a move coinciding with the rise of modern science. This rejection of empirical claims for supernatural manifestations transferred claims of religious "knowledge" to the realm of personal, mysterious experience, a realm that was unshareable, unmediated, self-authenticating, and irrefutable. Religious experience became radically private and unavailable to the nonreligious. In this move away from religious empiricism, theology seemed to yield reasoning entirely to science, suggesting that authentic religion is noncognitive altogether. Hufford, however, resists this claim and finds in belief in religious healing both an internal

rationality and a desire and effort to cite empirical—if unrepeatable—evidence.

Hufford describes the believer's reasoning process in two types of belief in religious healing. (In the course of the article, Hufford narrows the range of his field from general religious healing to Christian practices, and then almost exclusively to the practice of prayer.) In general, Hufford begins, when a believer in God encounters sickness and suffering, a crucial epistemological-existential-theological issue arises: if God is good, real, and powerful, why must innocent people endure suffering, such as sickness? This is the question of theodicy, the justification of God in the face of evil. Within modern Christian healing traditions, Hufford finds two broad views of theodicy, which he calls the "you-will-be-healed" view and the "you-may-be-healed" view. The first leads the believer away from medical care (belief requires faith in the efficacy of God's power alone), while the second usually functions as an added resource that does not conflict with medical care (medical treatment is one expression of God's efficacy). Both are logical in that they follow properly from their premises. Their different understandings of what causes illness and healing determine the empirical support they offer believers.

The premises of the you-will-be-healed view are that Christian scripture is true and that miraculous healing does occur. Because God wills all to be healthy, suffering is a consequence of individual sin (that is, the truly innocent do not suffer). Following this logic, suffering is a personal rebuke, and one must expiate and avoid sin for the suffering to end. If one prays, repents, and rectifies one's life, God will miraculously heal one physically. If one is not healed, then he or she is still in sin, of insufficient faith, or not praying correctly.

The you-will-be-healed position solves the problem of theodicy and leaves no mystery. For the sufferer it offers a guarantee of release from suffering, and for the well it offers an endorsement of their spiritual condition and a prediction of continued temporal well-being. This position enjoys an internal rational coherence, and many of its premises appeal to a kind of empirical support. For example, when healing does occur, it is due to God's will and to the believer's repentance. The fact that the supplicant does have complete faith, for example, cannot be proven, even by the supplicant, by anything other than a successful

healing; failure to be healed impugns the supplicant, not the belief. This view also rules out the possibility of seeking medical care: if one must show absolute certainty that one will be healed by prayer alone, one cannot logically accept medical therapies also. This is not to say that adherents to this view do not believe that medicine is effective. Rather, they think there are more effective methods for healing, methods that can lead to salvation as well as health.

The second position, the you-may-be-healed view, begins with several of the same premises as the first: Christian scripture is true, miracles occur, and God is good and all powerful. Although according to this view God's will is mysterious, it does not propose that human reason cannot make any sense of divine mysteries. Also, although suffering is a consequence of the reality of sin in the world, the role of individual sin is reduced, and the correspondence between particular sins and particular evils is removed. If one believes, for example, that original sin has led to an imperfect world, then God does not guarantee health in this life even to the best of believers; however, miraculous healing still may occur. In this view, medical care is among God's ways of healing. It follows that, in any case, whatever happens to the believer is spiritually for the best.

Both positions enable the believer to cope with sickness for which medicine may not provide a cure, combining both medical and religious concerns arising from illness. Both positions enable believers to receive social support, permit the consideration of alternatives, and allow for assessment of empirical evidence. Neither necessarily contradicts medical knowledge nor claims that medical care is ineffectual. Some basic assumptions, such as the one that God exists, supported by observations from everyday life, underlie the knowledge claims of those who believe in religious healing. Perhaps most crucially, religious belief involves the crediting of subjective experience that goes beyond "medical inexplicability." Believers in miraculous healing from God base their belief not only on the occasional patient who gets well but also on a wide variety of direct spiritual encounters. The prevalence and cognitive impact of such direct experiences have been given little consideration in efforts to understand the persistence of religious belief in the modern world. Rather than explaining away this persistence by calling such belief superstition, special

logic, or psychological compartmentalization, Hufford suggests that the mystical experiences deserve study inasmuch as, for many believers, these experiences move belief in God from mere assumption to empirically based knowledge.

—Edwin R. DuBose

Observing shiva

Joyce Slochower, "The Therapeutic Function of *Shiva*," *Tikkun* 8, no. 3 (May/June 1993): 51–54.

PATIENTS DIE, AND MANY OF THE CRITICAL ISSUES that engage clinicians and bioethicists concern attempts to adjudicate situations surrounding death. But when decisions have been made and issues resolved, when ethicists can "do no more," they, like physicians, tend to move on, their task completed. Others—specifically, the patients' families and loved ones—must deal with the aftermath and long-term consequences of decisions. But rarely is this aftermath taken into account in ethical analyses. Even less frequently is it seen as appropriate for ethical analysis. This is particularly problematic in a culture that eschews death and no longer shares practices that might give death and mourning a meaningful context.

It is in this situation that Joyce Slochower's thoughts in "The Therapeutic Function of *Shiva*" can offer a new paradigm for ethical reflection, especially with regard to medical decisions at the end of life. Slochower skillfully combines insights derived from psychological theory and her experience as a practicing psychoanalyst with her own experiences of the Jewish mourning ritual of *shiva*. The result is an interpretation of a seemingly archaic Jewish practice that illuminates ways in which religious ritual can respond to the moral complexities entailed in giving care and carrying on in the face of dying and death.

Slochower's brief essay interweaves three topics: (1) details of the observance of *shiva*; (2) a psychological interpretation of the dynamics embodied in the ritual; and (3) difficulties entailed in *shiva* and distortions of the practice.

The "laws" that prescribe the observance of *shiva* seek to help the mourners express their grief in concrete ways. Traditionally, *shiva* lasts for seven days during which mourners remain at home and symboli-

cally withdraw from the world to face their loss without distraction. Mourners forbear practices that symbolize vanity, comfort, or joy: they do not wear leather shoes, bathe, change clothes, use cosmetics, cut hair, engage in sexual contact, or study Torah. They are freed from the practices of social convention: all household tasks, answering the door (which is left ajar), or rising to greet a visitor. Mourners, while free to walk, stand, lie, or sit, are to use low stools or chairs to symbolize their lowered emotional state. They tear their outer garment at the moment of death or at the funeral and do not change this garment throughout the shiva period.

While these practices concretize the mourner's grief, other practices help keep both mourner and house callers focused on mourning. All in the community are to pay shiva calls, regardless of their relationship with the mourner. Upon arriving, callers must wait for the mourner to greet them and initiate conversation, thereby allowing the mourner to direct the conversation (whether to their grief, to thoughts of the deceased, or to other topics) or to maintain silence. Traditional farewells are prescribed, again to keep focus on the purpose of the visit.

For Slochower, though shiva "at first seems a rigid set of rules," it embodies a brilliant prepsychoanalytic wisdom: it serves the therapeutic purpose of facilitating mourning and healing by creating a "holding environment," "an emotionally protective setting within which the patient can expose private experience" (p. 52). In shiva, this "hold" is collectively produced by the community of shiva callers. It provides not only emotional space—to talk about the deceased or other subjects as desired, to stay with feelings of loss as long as necessary—but also concrete care—a minyan for Kaddish, the Shabbat meal, food for one's family, and company that "freed me from the burden of having to ask for the company that I did not always know I needed."

Slochower is critical of distortions of shiva, noting that "for many, 'sitting *shiva*' has come to describe a brief social afternoon following a funeral, during which the mourners provide a spread for the guests" (p. 51). In these instances, shiva becomes a burden rather than a support for the mourner, distracting all involved from "the uncomfortable knowledge that the mourner is in acute pain."

Although Slochower does not make explicit cor-

relations, she identifies a number of factors that contribute to the distortions and inaccessibility of practices like shiva. As a culture, we find ritual awkward and therefore unfamiliar, forced, "unnatural." Further, by minimizing distractions, shiva forces participants to face that which makes us very anxious, namely, the reality of death. By intentionally bracketing social convention—"to enter a shiva house and not to greet anyone, to sit in silence (often among a group of strangers) waiting to be acknowledged"—the shiva call can be "intensely uncomfortable." Finally, in spite of the laws, it is difficult to know what to expect during a shiva call: people experience their loss and grieve in different ways, from sobbing to anger directed at the caller to denial. But although Slochower admits she found making shiva calls painful, uncomfortable, and often superficial, she became aware of their power when she became the recipient of such calls: "they made me aware in an immediate sense that I was part of something larger than myself or my grief."

Another reason for the atrophy of such observances may be the atrophy of community. As Slochower notes, "the shiva setting makes a demand on the community: to permit the mourner to use people within the community without regard for the community's needs." But at the same time, shiva laws recognize the intensity of these demands on the community and set limits. Shiva calls are short and structured. The "holding function of shiva is . . . shared by the community, falling lightly on its individual members." It is temporally circumscribed: "on the seventh day of shiva, the mourner must 'get up' whether emotionally ready or not." This radical break may "actually begin to draw the mourner back into life." Further, "shiva is interrupted by Shabbat, and is actually cancelled by major holidays." Thus shiva places the mourner's need in the larger context of community need and reflects the community's need to remain engaged in life.

Slochower calls for a return to shiva observance, seeing it as "a gift that you can provide yourself when you face a death, and one that you can offer others in the same circumstances." Consideration of the meaning and practice of shiva might similarly enrich bioethical reflections on medical decisions at the end of life.

—M. Therese Lysaught

On the beginning of life

Lisa Sowle Cahill, "The Embryo and the Fetus: New Moral Contexts," *Theological Studies* 54, no. 1 (March 1993): 124–42.

Lisa Sowle Cahill, "Abortion, Sex and Gender: The Church's Public Voice," *America* 168, no. 18 (22 May 1993): 6–11.

SOMETIMES IN A SEEMINGLY ENDLESS DEBATE, someone offers an analysis that clarifies the argument and furthers dialogue by reorienting the participants to a broader context often overlooked. In these two articles, Lisa Sowle Cahill provides such relief to those engaged in the Catholic beginning-of-life debates. The first article critically summarizes current Catholic arguments regarding "personhood": What scientific evidence and normative theory allow us to set the beginning of personhood for the embryo or fetus? The second article reminds us of the debate's context: How has the Catholic message on abortion, sexuality, and women affected the church's credibility "in-house" and in the public debate?

In "The Embryo and the Fetus: New Moral Contexts," Cahill scans the most recent developments concerning the moral status of embryos and preembryos. She helpfully crystallizes the central question, "whether full moral status in the human community ('personhood') can be tied to a physiological indicator or developmental line" (p. 124). In other words, what is the relationship between scientific findings and normative philosophical positions?

The current debates are catalyzed by recent developments in genetics and embryology. We now know that fertilization occurs over a 24–36 hour period; that the embryo needs some genetic cues from the mother for its development; that the "primitive streak" that appears at implantation marks a number of shifts in developmental focus, most significantly the integration of embryonic cells to prevent twinning and the stabilization of the embryo's individual identity. These developments create practical issues regarding selection of some in vitro embryos for implantation and disposal of others; genetic testing of embryos and genetic counseling; use of the new abortifacient birth-control drug RU-486; and use of aborted fetal tissue for research.

For Cahill, these controversies have two "centers." The first, which she calls empirical and descriptive, concerns whether or not the best current medical and scientific data can support the view that "individuality and integrated functioning of the organism can be set at the time of fertilization." The second, which she calls philosophical and normative, asks how "data" ought to be interpreted: What does the term *person* mean in relation to particulars of human existence? What are the minimum criteria for personhood? Cahill concludes that opponents in the debate interpret and explain the "data" according to previously held theoretical commitments, each citing different results and calling upon their own experts. Because scientific study is rarely conclusive and always changing, Cahill recommends that moral theology "learn to live with ambiguity, avoiding the paralysis of judgment on the one side, and the tyranny of preconceptions on the other."

Having issued this caution, Cahill carefully reviews recent Catholic discussions of preembryonic personhood, focusing on the central conceptual warrant: *potentiality*, or the potential, over time, for a conceptus to develop the "characteristics of fully realized persons" (p. 128). Both sides within the Catholic debate appeal to potentiality but may mean very different things. On the one hand, if the end or outcome—that is, full human personhood—is of value, then any stage in development toward that end has as much value as the end. This understanding supports the position that personhood is established at fertilization (a position represented by Antoine Suarez and Germain Grisez, Nicola Poplawski and Grant Gillett, Augustine Regan, Stephen Heaney). On the other hand, if the end or outcome has complete value, preceding stages in development will draw their value from the end, but their value will be proportional to their stage in the process. This understanding leads others to confer different moral statuses on different stages of development (a position represented by Norman Ford, Carlos Bedate and Robert Cefalo, Thomas Shannon and Allan Wolter, Richard McCormick, and Thomas Bole).

For those in the latter camp, *individuality* determinatively distinguishes between stages of development. (*Individuality* is the term used, although the term *individuation* would probably be more accurate.) Drawing on recent scientific findings, they argue that

"as long as the cells of the zygote are in their totipotent state, or while twinning is possible," individuality has not yet been established. Moreover, they rebut the argument of genetic uniqueness, citing evidence that external genetic material from the mother is required for embryo development. Thus during the first 14 days it is highly improbable that the preembryo is a person—"it is only at the primitive-streak stage [that is, at implantation] that ensoulment can thus take place" (p. 129). Up to this point, therefore, the preembryo does not have human rights. Even so, those who make these arguments will want to afford some value to the preembryo, especially for the purpose of research policy; McCormick, for example, asserts "a 'strong' but still 'prima facie' obligation to treat the preembryo as a person" (p. 132) to guard against a diminishment of respect for human life.

Those who hold that the soul must be present from conception onward argue from a Thomistic philosophical framework regarding form and matter and from the axiom that "an effect must not be greater than its cause" (p. 135). For those who draw on Thomistic philosophy, "a rational soul . . . is responsible for the development of the person; . . . this soul is the form of the new individual" (p. 135). Others argue that a soul does not develop, cannot be infused at some point along the developmental path, and so must be present from the moment of conception. To believe that the soul enters later, they suggest, requires an unhealthy dualism. They even imply that the soul *directs* the development of the conceptus (p. 136): those that spontaneously abort or become hydatidiform moles lack a soul; those that become multiple births do so perhaps because they are directed by multiple souls. Cahill also briefly notes a division within the developmental camp. In addition to biological individuality and integrity some require that the "potential" person also have "psychological integration" (Bole) or sufficient neural development to support self-consciousness and rationality. Shannon and Wolter suggest that the biological potential for rationality can be set at no earlier than eight weeks.

Is the debate at a perpetual stalemate? Cahill does not think so and draws three conclusions. First, that there must be a dynamic relationship between science and philosophy: scientific "facts" are always interpreted within theoretical frameworks, but theoretical frameworks require scientific "facts" to interpret.

Second, she recommends a broader view of these issues and suggests that we step back from the immediacy and heat of the argument to see things within the broader context of history and our various cultures. She appeals to a common moral sense found in the shared moral ethos of a community. This is not, however, a naïve common sense of the masses prone to arbitrary and morally regrettable conclusions. This common sense is refined as the community struggles with differing worldviews and challenging new experiences that cannot be accommodated by old understandings and practices, that demand deep reflection and change.

Finally, because no viewpoint is objective or can transcend our immersion in culture and history, Cahill maintains that we must examine the moral order and the common problems of our community as a team. We must share tools and insights with our contemporaries and other cultures, races, and creeds. This requires that we approach facts, values, and programs for action with humility, empathy, prudence, and a moral courage that signifies the ability to concede and to listen. The debate will only advance, says Cahill, if we work with mutual respect, make inferences cautiously, and self-consciously scrutinize our value judgments relative to the problems and social practices that initiated the moral debate. She concludes that dialogue about the personhood of the embryo and fetus should be carried on not only by representative national bodies but also by local communities.

In "Abortion, Sex and Gender: The Church's Public Voice," Cahill turns from the philosophical nuances of the Catholic debate to its social context. She does so by giving an illuminating account of her personal experiences with different Catholic factions. For instance, although Cahill sees herself as a moderate, at a conference sponsored by Catholics for a Free Choice she realizes she was invited "as a lone 'pro-life' presence," while at another conference designed to defend the prolife position she is the "token feminist."

Although in these experiences Cahill was placed at opposite poles of the Catholic debate, she notes that in the wider national debate on abortion, American Catholics are generally "all within about three notches of the right end of a spectrum reaching from one to ten" (p. 7). Both "liberal-progressive" and "conservative-traditional" Catholics tend to value life at all

stages, generally oppose abortion on demand, and believe that their views do not simply represent narrow religious doctrine but are defensible on humanistic and philosophical grounds. The danger is that Catholicism may waste its energy and become publicly irrelevant by "counterproductive infighting" over issues like prolife compatibility with feminism and litmus-test allegiance to the idea that life and personhood begin at conception.

Cahill calls for a change in the focus of this family dispute away from the right to life of the unborn and toward the social and cultural factors contributing to the decision to have an abortion. She disapproves of the "crusade mentality" used by those whose motivation comes from compassion for the most vulnerable. She suggests that Catholics find common ground with cultural values that might be the basis for abortion alternatives. To ignore these challenges is to risk sectarian isolation from the world of politics and social institutions.

Cahill helpfully reminds the Catholic reader that focusing on the personhood question diverts attention from the context of the abortion issue, namely, the issues of sexual morality. She reminds Catholic leadership that "sexuality cannot be addressed without looking at gender roles and relationships" (p. 7). In a powerful and not-so-subtle indictment, she states:

In addition to the value of unborn human life, the "Catholic message" on abortion includes its teachings about the intrinsic relation of sexuality and parenthood, about the reciprocity and shared responsibility of women and men in the family, about human sociality and interdependence in contrast to liberal individualism and about social justice as social participation for women as well as men. Unfortunately, the power of this message on abortion is undermined by the church's record on women's roles, and by a continued teaching on sex that ties its purposes too closely to the procreative structure of isolated sex acts. (P. 7)

As Cahill puts it, "We need a 'consistent ethic of sex.'" She develops her views in five points.

1. Because scientific knowledge about the early stages of human life is in progress, there is room for nuance, uncertainty, and reasonable disagreement on the question of the personhood of the fetus. To provide a credible social defense for gestating human life, all

parties in the discussion should be willing to engage differences of judgment on the moral status of the fetus in good faith.

2. The character of the pregnancy relationship—in which one human person is dependent on another in an unrepeatable way—is morally unique. Though the woman has, Cahill believes, a special obligation to her unborn offspring, the fulfillment of that obligation places burdens on her unlike those in any other case. The prolife position must address this sacrifice and thus the issues of equality for women in the sexual-moral sphere and in society.

3. The church's support for pregnant women provides only short-term help and does not address the reasons behind unplanned pregnancies. A profound change is needed in the sexist and individualistic social attitude that sees pregnancy as the woman's problem, that gives women a choice only between abortion and sole responsibility for the child. Women must be given the emotional and material resources to deal constructively with unexpected parenthood.

4. Though Catholic social teaching has begun, according to Cahill, to move toward gender equality and toward relationship as the key to sexual meaning, it still links those values to a worldview that upholds an oppressive, idealized maternity as the definitive female role, and procreation as the only legitimate reason for sex. This narrow focus obscures other valid, socially relevant church teachings on sexual maturity, commitment, and the meaning of marriage.

5. The church's moral leadership and involvement in the public debate on abortion will be only as strong as the success of its appeal not just to religious authority but to an objective moral order that all people can understand. Hence the natural law argument might be used, but only with the recognition that notions of rights, natural law, or justice may not be self-evident. When Catholicism proposes what it sees as a moral truth on abortion or sexuality, it must connect that message to related social concerns about women's equality and economic constraints on families. The church can foster alliances with those Americans unwilling to take away women's rights to abortion but also dissatisfied with abortion on demand, thereby finding common ground to promote social measures that will reduce abortion, even if not outlawing it.

—Agnes Coveney
Research Assistant

Care of the dying

Catholic Health Association, "Care of the Dying: A Catholic Perspective," *Health Progress* 74, Part I, "Cultural Context" (March 1993): 34-38, 70; Part II, "Social and Political Context—Catholic Providers Must Exemplify a Caring Community" (April 1993): 16-21, 41; Part III, "Clinical Context—Good Palliative Care Eases the Dying Process" (May 1993): 22-26, 31; Part IV, "Theological, Moral, and Pastoral Response—The Transformation of Suffering" (June 1993): 46-54.

PHYSICIAN-ASSISTED SUICIDE IS GAINING increasing public and professional support as a humane alternative to an institutionally and technologically managed death. This series of articles responds to this trend by forging a Catholic perspective that addresses the contributing factors and that can also serve as a resource in the care of the dying. The essays deal in turn with the cultural, social, political, and clinical contexts in which care of the dying occurs, and with a theological, moral, and pastoral framework for approaching that care.

Culture plays a significant role in how people understand and experience death and in how they care for the dying. Four characteristics of American culture must be taken into account if the health care community is to foster positive attitudes toward death and to help the terminally ill to live well while dying. The first characteristic is the large number of people who die in health care institutions: an estimated 80 percent of all reported deaths (Part I, p. 35). Institutional policies and procedures are frequently depersonalizing and can cause people to feel out of control. This reality makes it all the more important to give the treatment preferences of competent patients a central place in the patient-caregiver relationship.

The second factor is the ethos of individualism that pervades American culture and that sometimes leads to an exaggerated faith in self-determination. Personal autonomy, however, is not absolute. It is limited by our living in a community of interdependent persons, by the reality of sickness, and by the sovereignty of God. The ethos of individualism also poses a serious threat to the care of the dying by inhibiting the human bonding that creates the interdependent community that, in turn, enables in-

dividuals to flourish. To flourish, patients must be allowed to retain as much control as possible within the limits of belonging to a community. In addition, their network of relationships needs to be secure so they can experience the bonds of trust and love that support personal dignity and enhance the meaning of life.

The third cultural factor that needs to be taken into account is the heavy reliance on technology in American medicine. This can discourage patients, families, and caregivers from facing human limits and can subject patients to the tyranny of technological domination. The increased interest in legalizing assisted suicide and euthanasia correlates with the increased fear of being trapped in unacceptable conditions of dependency and disability. The overuse of technology can end up overwhelming human freedom and becoming a substitute for the healing touch of interpersonal relationships. Technology should instead aim at the total good of the person, which means trying to achieve cure or relief as well as respecting the patient's preferences, values, and what the patient regards as giving ultimate meaning to life.

The fourth cultural characteristic of American society is its pluralism. Institutional protocols can deprive patients of powerfully symbolic expressions of meaning, love, and hope that come from religious, ethnic, national, or familial traditions. Care of the dying is impoverished if the patient's cultural context and resources are ignored. Health care givers are challenged to respect the diversity of patients' social and religious values.

When it comes to addressing the social and political dimensions of end-of-life issues, Catholic health care providers must use clear and consistent definitions of terms such as death, death with dignity, the right to die, euthanasia, allowing to die, mercy killing, suicide, assisted suicide, and persistent vegetative state. Also, because the media not only reflect but also create attitudes toward death, health care institutions must seize opportunities to educate the media and to provide public education on fundamental human and religious values. On the political front, health care institutions should work for legislation that balances the rights of the patient, the conscience of the health care provider, and the interests of the state; this includes support for advance directives. In addition, health care institutions should assume a leadership

role in transforming current policy and practice into more humane and dignified methods of making decisions about treatment.

Clinically, Catholic health care institutions must provide good palliative care and support for the dying. For most people, it is not death itself that is most feared but rather the dying process. One of the primary purposes of medicine is to relieve pain and suffering. More than 90 percent of physical pain can be relieved, yet it is estimated that as many as 75 percent of terminally ill patients are inadequately treated, and 25 percent die in severe, unrelieved pain. Whether because of lack of knowledge of the doses needed to combat severe pain, fear of causing respiratory distress, anxiety about the hazards of addiction, fear of civil or criminal prosecution, or an overestimation of the side effects of some analgesics, physicians are clearly failing in the treatment of pain. In order to relieve pain adequately, caregivers need to formulate policies for the acceptable use of narcotics and be trained in the various methods for controlling pain; medical students need to be trained in pain management; pharmaceutical companies need to educate qualified professionals on the proper use of pain medications; and statewide consultation networks for managing pain need to be developed.

In addition to the relief of physical pain, Catholic health care institutions must be committed to the management of psychological, social, and spiritual pain. Terminally ill persons experience an overwhelming sense of loss of control, a threatened sense of purpose and meaning, and a weakened sense of being connected to others. They have a great need for support to help them deal with denial, anger, guilt, and fear; for relatedness to caregivers and family; for frameworks of meaning to help them make sense of their experience; and for truthful communication. The latter lies at the heart of the patient-caregiver relationship, and entails, among other things, tact, timing, style, and an open, ongoing conversation. Several suggestions are offered to caregivers to help foster better communication.

Furthermore, it is incumbent upon Catholic health care institutions to organize themselves inter-

nally in order to offer optimal support programs for the dying, for families, and for caregivers. This might include integrated treatment plans using a collaborative team model, creating a hospitable environment, developing good institutional policies that respect advance directives and foster collaborative decision making, forming and using institutional ethics committees, and employing a hospice philosophy of care for the terminally ill.

Finally, Catholic health care professionals are called upon to give meaning to situations that seem meaningless and to respond in ways that express faith and offer patients hope. One of the most important contributions of Catholic health facilities is to help patients in their struggle to find meaning in suffering and death from the basic conviction that life, not death, has the last word. In addition, the healing community, in its care of the dying, must embody virtues that bear convincing witness in both a personal and corporate manner. Opposition to assisted suicide is not sufficient; nor is adherence to the principles that guide a Catholic understanding of life and death and that shape a Catholic view of assisted suicide—sanctity of life, God's dominion and human stewardship, and the prohibition against killing.

There are three characteristics of the virtuous community: interdependence, which involves establishing relationships based on trust and honesty and collaborating with other communities that have an interest in the care of the dying; care, which entails persistent presence, careful listening, courage, perseverance, compassion, humility, patience, hope, and a willingness to enter into another person's life to help carry that person's burden; and hospitality to the patient and his or her family, which can frequently be achieved through hospice care that seeks the patient's total good, improves the conditions of dying, and reaches beyond a patient to his or her network of support. "By being a virtuous community of interdependence, care, and hospitality, the Catholic community gives witness to the convictions that lie behind the arguments we use to oppose the practice of euthanasia" (Part IV, p. 54).

—Ron Hamel

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Examples

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