THE ETHICS AND POLITICS OF CAREGIVING


Caring for Our Elders: Multicultural Experiences with Nursing Home Placement, by Patricia J. Kolb. Columbia University Press, New York, 2003, 191 pp., $70.00 (cloth), $24.95 (paper).


Informal caregiving is the backbone of our long-term care system, and we often hear pious expressions of appreciation from policy makers for the sacrifices that caregivers make to keep the system afloat. I don't think this piety ("doing God's work") is entirely hollow but it is a poor substitute for the kind of publicly provided support for caregivers that is increasingly available in other developed countries. Each of the three books reviewed in this essay addresses this contradiction between the value we say we place on caregiving and the absence of much material expression that we actually hold this value dear.

The Challenges of Informal Care

The number of relatives and friends who provide some level of long-term care in the community is now close to 30 million, and their unpaid care is estimated to
be worth between $275 and $300 billion annually, which is roughly twice what we pay for formal long-term care provided in nursing homes and the community. In the opening chapter of *Always on Call: When Illness Turns Families into Caregivers*, the editor, Carol Levine, provides an overview of what these caregivers are doing by summarizing the major findings from the national survey Long-Term Care from the Caregiver’s Perspective, which was conducted by the National Opinion Research Center in 2002. The survey found that: many caregivers are in vulnerable health, with 32% reporting serious health problems; caregivers provide an average of 20.9 hr of care per week; 40.8% had been caregivers for more than 5 years; most are providing personal care and household tasks but up to 40% are providing some form of medical care; a high proportion received no instruction in caregiving tasks (56% were taught nothing about ADL care); only 9% to 18% hired or arranged for additional paid help; and 18% reported a need for help in the previous year that they were unable to obtain, mainly because of access-related and financial difficulties. These are the caregivers who suffer most from the absence of a publicly provided infrastructure of caregiver support services in most communities. They also suffer from what Levine describes as a “push toward a health care delivery and financing system that uses hospitals and professional and public resources sparingly and patients’ homes and family caregivers liberally” (p. 4). These trends toward an increasing reliance on family caregivers are generated by market-driven efforts to contain health care costs through

... reduced length of hospital stays, increased outpatient and community-based care, and reductions in home care benefits available through insurance, managed care organizations, or public programs. Individuals and families are under increased pressure to pay more direct costs. At the same time, with the emergence of industries marketing high-tech medical equipment for home use, families are expected to provide ever more hands-on, often technologically complex care.

These economic and technological developments mean that family caregivers are being asked to shoulder greater burdens for longer periods of time, and to forgo more educational, career, and social opportunities for themselves. Indeed, the human and social costs of maintaining patients at home are very high (p. 4).

Levine and her authors cover most of the essential dimensions of caregiving, including several richly detailed and emotionally powerful caregiver narratives that touch on a wide range of caregiver experiences. These intimate accounts reflect the grinding hardship, mundane routines, constant challenges, and spiritual fulfillment of caregiving. Rabbi Gerald L. Wolpe describes the “daily struggle to make certain that the heart remains supple and responsive” (p. 43) during 17 years of caring for his wife.

Levine describes the loneliness she experiences as a caregiver abandoned by a health care system designed to treat the injured and acutely ill “but then consigns such patients and their families to the black hole of chronic ‘custodial care’” and holds family members “to a level of moral or legal responsibility that entails jeopardizing their own health or well-being.”

Robert L. Kane and his sister Joan C. West describe the deeply frustrating efforts they made to arrange a reasonable quality of care for their independently minded mother who needed extensive services following a stroke. Kane has been a major long-term care researcher and theorist for decades, and he brings his deep knowledge and awareness to the task of describing how our long-term care system failed his mother during the last months of her life. Kane and West conclude that based on their experience, we need to develop a hybrid program that will close the gap between assisted living and nursing homes—a program that will provide more care than the former and a more livable environment than the latter. I think that a hybrid program of this kind will emerge during the next few years, but it will require extensive reworking of current regulations and funding strategies.

The other chapters in this first section are all valuable additions to the literature of first-hand accounts of the caregiving experience and will resonate with many readers as they think about similarities with their own caregiving experiences. I think the accumulation of these narratives is important in making the moral argument for holding policy makers accountable for the rampant neglect of long-term caregivers and care recipients and in building political support for fundamental changes in our long-term care system.

The second section of *Always on Call* consists of six chapters addressing the impact of caregiving from several perspectives, including the emotional experiences of caregiving, the poor fit between caregiving responsibilities and the workplace, caregiving at the end of life, the role of social workers in caregiver advocacy, and the financial impact of caregiving—which is substantial and will not be made any easier by the new bankruptcy law. This egregious bit of “bought” legislation is likely to further stack the deck against many families brought to the financial edge by caregiving costs. Levine and Connie Zuckerman suggest that the negative impact of caregiving can be reduced by adopting an ethic of accommodation that is cognizant of the stresses faced by family caregivers and is committed to overcoming bureaucratic rigidities and maximizing support for them. This ethic is consistent with the focus on empathy, negotiation, and equality in the communicative ethics of Habermas, which Harry Moody (1992) first applied to long-term care policy and practice in his seminal work, *Ethics in an Aging Society*. It is also consistent with the feminist ethic of care that argues against a rigid adherence to rules and emphasizes responsiveness to the needs of others in a context of equality and mutuality.

The third section on responding to caregiver needs includes a fine survey of current caregiver support programs by Lynn Friss Feinberg, a long-time scholar and advocate for caregiver services. She begins with a description of the National Family Caregiver Support Program, which was added to the Older Americans Act...
(OAA) in 2000, and is administered by the Administration on Aging and its aging network, which consists of state units on aging, area agencies on aging, and nonprofit service providers. The program received $155 million in 2003 and has been used by the aging network to provide a wide range of caregiver support services, including respite care. The program has garnered mostly rave reviews everywhere. Its only shortcoming is that there just isn’t enough of it; the funding is a small fraction of what is needed, which is, of course, the whole story with the OAA. The OAA now purchases about half the services it did 20 years ago, due to stagnant funding and the growing need for community services.

Feinberg also discusses several other relatively small-scale, mostly state-funded caregiver support programs. One of the most promising of these programs is consumer-directed care (CDC), which has the potential to become a major part of the community-based long-term care system over the next few years. Evaluations of CDC programs in California and other states indicate that giving consumers control of resources, which are often used to pay family caregivers a modest income, is cost-effective, especially in terms of consumer satisfaction and caregiver support.

Community-Based Formal Services

Carole B. Cox’s book, Community Care for an Aging Society, is an efficiently written overview of the current array of community-based services for the elderly. The author also provides brief assessments of the strengths and weaknesses of these services, identifies service gaps, and offers policy recommendations. One of the major strengths of the community-based system is that the aging network provides the infrastructure for the community-based long-term care system in most states and could become the vehicle for a far more comprehensive and integrated approach to long-term care than is now the case in most areas of the nation. The aging network, however, in all but a few states, does not have the resources needed to individualize services, coordinate their delivery, and link them efficiently with the efforts of informal caregivers.

Cox notes that the aging network has relied on Medicaid home- and community-based waiver funds to expand long-term care services during the last several years. This strategy, for all of its positive features, limits the availability of services to those who meet restrictive Medicaid financial and level-of-care-needed criteria. This means that a growing population of elderly people who lack the individual or family resources to meet their long-term care needs are not getting the help they need. Many of these people go without care until they are so impaired that their only option is to move into a nursing home where Medicaid, once their resources are depleted, will pay for the cost of care at $40,000 or more a year.

Culture and Long-Term Care

Patricia Kolb covers many of the same topics as Cox in her book, Caring for Our Elders: Multicultural Experi-
ences with Nursing Home Placement. Kolb’s observations and recommendations are drawn from a review of the long-term care literature and an analysis of case records and interviews with residents of a large, ethnically diverse nursing home and their caregivers. Kolb makes a strong case for shifting the center of long-term care policy and practice from the long-term care industry to the long-term care recipient, her social network, and her cultural experience. A resident-centered focus that does not separate the resident from her family, community, and culture cannot be achieved in a nursing home environment dominated by regulations and standards of care based on the medical model of hospital care and by a market-driven approach to the allocation of resources. These twin forces tend to instrumentalize the way care is provided, marginalize concern for the emotional lives of residents, and reduce them to the status of commodities. These are not new criticisms of our nursing home-dominated system of long-term care for elders, but they bear repeating, especially when they are embedded in the kinds of lived experiences Kolb uses her interview data to describe.

Kolb extends her critique well beyond the deficiencies of nursing homes by pointing out several other issues: Workforce problems (shortages and turnover) are endemic to the entire long-term care system and will get much worse soon; greater cultural competence could very much improve the long-term care quality of care and life for minority elders; housing with services is becoming increasingly scarce for low-income elders; community-based care is still more concept than reality in most communities; and these and other shortcomings in our long-term care system reflect the absence of a deep, organizing commitment to creating a humane and effective long-term care system for nonaffluent elders.

Many critics, especially feminist writers, claim that the lack of support for informal caregivers and the stepchild status of long-term care issues among policy makers are a result of the fact that long-term care is largely the work of women who have historically provided 75% or more of the care in both the formal and informal sectors. Other cultural factors have also contributed to the devaluing of caregiving, including the fear of aging, the view that caregiving is a less important than more productive and productionist pursuits, and a deep societal bias against the public provision of welfare services. The dominance of women in long-term care, however, cannot be discounted as a source of our deep ambivalence about its value.

As the findings from the national caregiver survey summarized by Carol Levine indicate, however, an increasing number of men seem to be taking on the caregiver role, at least in the informal sector. This trend, because of our shifting demographics, is likely to continue, or even accelerate, over the next several years. Given the survey’s broad definition of a caregiver, however, it remains unclear as to whether men are modifying the gender-specific caregiving duties they have historically performed (e.g., household repairs and arranging for paid or unpaid help provided by someone else). The survey demonstrates that, despite
their increased participation in caregiving, men continue to lag behind women in both the quantity and intensity of the care provided.

The Public Policy Challenges

With increasingly fewer women available to provide “free” caregiving services for a rapidly increasing population of frail elders and more men being called on to meet the caregiver shortfall, the demand for more public sector support of community-based long-term care services is likely to grow. The odds are, however, that substantial increases in long-term care spending will not become a compelling political priority until federal budget deficits are curtailed and an effective resistance to the neoliberal policy agenda emerges. This agenda has gained dominance by persuading a large share of the electorate and the policy elites that lower taxes on the wealthy, reduced funding for domestic programs, and increased reliance on a deregulated market are essential for a prosperous economy.

Whatever prosperity this agenda has achieved over the last four years is largely one-sided with benefits accruing from increased productivity and profits going almost exclusively to the top 10%, mainly the top 1%, of income earners and asset holders. On the other hand, however, average wages have stagnated, savings have declined, and family debt levels have grown. The Bush tax cuts have reduced federal revenues as a percentage of GDP to the lowest levels (16.5%) since the late 1950s. The federal budget deficit is projected to grow by at least $2.0 trillion over the next 10 years and by much more after 2013, if the tax cuts of the last four years are made permanent.

These economic trends do not support an optimistic view of the nation’s capacity to provide income and health care security for the next generation of retirees, the baby boomers. The accumulating federal debt is probably most threatening to the fiscal stability of Medicare and Medicaid. The latter is the biggest payer for long-term care services. Retirement security, based on an intergenerational compact embodied in federal tax and spending policies, is not a priority of the neoliberal social philosophy, which holds that the individual and her family are fundamentally responsible for securing their own well-being, with the state providing some start-up resource (education) and a minimal safety net. For many advocates of neoliberalism, even this minimalist state is not limited enough; they would prefer complete privatization of education, social and health services, and the reduction of the public sector to arch-conservative Grover Norquist’s “wad of toilet paper” that could be “flushed down the toilet.”

Publicly supported long-term care cannot be maintained at even its current underfunded level, much less enhanced through improvements like comprehensive caregiver support services, unless some effective means are found over the next few years to resist the neoliberal hierarchy of values and the fiscal and social policies that follow from those values. Advocates for elders and retirement security should be in the forefront of efforts to create this resistance by developing an alternative social vision, a policy agenda, and political strategies that are more responsive to the lives of ordinary people in their efforts to achieve a reasonably secure retirement.

Successful efforts to prevent the privatization of Social Security are a necessary, but far from sufficient, strategy for protecting the interests of retirees and their families. We will need a more comprehensive approach embracing public and private pensions and health care and long-term care, and one that is based on a restored recognition of the moral truth that all of us, young and old, are at some fundamental level in this together when it comes to ensuring retirement security.

History and current pension and health care realities clearly indicate that an acceptable quality of life in retirement for most people cannot be achieved through neoliberal market strategies that force individuals to pay for their retirement on their own. Social insurance programs like Social Security and Medicare have proven to be far more effective than private schemes in preventing poverty and poor health care among elderly people for the last several decades. These programs have also proven to be more efficient than private pension and health care programs, which have higher administrative costs.

Instead of replacing successful social insurance programs with market-based approaches that ignore the policy lessons of the last 70 years, we should be preparing to extend them by providing more public support for long-term care, including far more funding to support informal caregiving. We cannot expect informal caregivers to continue bearing most of the burden of caring for a growing population of dependent elders if we are not willing to support them by subsidizing the work they do, implementing a paid family leave program, and creating a more seamless nexus between the formal and informal care systems.

This reversal of current policy trends may not seem politically feasible at the moment. But, I think, it could occur over the next decade in response to the declining availability of caregivers relative to the growing need for them (the caregiver gap), the increasing salience of long-term care as a political issue within the growing population of older voters, and the emergence of a critical mass of organized caregivers with a policy agenda. This reversal could also arise from a spreading awareness that the neoliberal privatization approach to retirement policy is not an effective, efficient, or morally defensible substitute for an ethic of care that binds the generations within families and the larger society. Perhaps the first real sign that such a reversal is underway will be successful efforts by policy makers to begin restoring the nation’s fiscal integrity and generating the resources required to sustain our publicly supported retirement system and to fund an ethic-of-care-oriented long-term care system.

I think it is possible that the growth of the older population and the need for caregiving assistance over the next several decades will have a salutary effect on our moral culture and related political priorities. For more than 20 years, shallow, materialistic values,
which are most vividly expressed in the greedy and unaccountable behavior of our corporate elites with their outrageous compensation packages, seem to have become as dominant in American culture as they were in the 1920s. I think this narrow focus on private gain has eroded the kind of communal values (such as generosity and compassion) required to valorize caregiving and give it paradigmatic status as a way of life. This may change as many more people are affected by the caregiving experience and come to understand the existential meaning of caregiver loneliness and the fundamental vulnerability of everyone. More of us are also likely to perceive the injustice of caregiver abandonment.

There is, I think, an inescapably religious dimension to the caregiving experience. The self-sacrifice entailed in caregiving may be the closest brush with transcendence that most people will ever experience. As it becomes more common, this experience has the potential to play a major role in transforming America’s moral culture and politics as we come to recognize the illusions of self-sufficiency and the realities of mutual dependence in a world of greater risks than the vast majority of us can bear alone.

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References