



## FROM BIRTH TO DEATH AND BENCH TO CLINIC

# THE HASTINGS CENTER BIOETHICS BRIEFING BOOK

for Journalists, Policymakers, and Campaigns

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### CHAPTER 14

## Family Caregiving

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# family caregiving

by Carol Levine

## Framing the Issue

Families have always taken care of their ill and disabled relatives. Why should it be any different now? This disarmingly simple question often opens a policy discussion of the role of families in providing care to aging or chronically ill family members. Underlying this question is an assumption that families should do everything they did in the fondly misremembered Good Old Days—and do it all on their own. In hospitals and other health care facilities, however, professionals often turn the question on its head: Why don't all these meddlesome families just stay out of our way? We don't have time for them.

Although family caregiving has always been an important kinship obligation, changes in demographics, workforce patterns, health care economics, and service delivery have resulted in a dramatic change in its extent and complexity. In this changed environment, what values should guide public policy in responding to family caregivers' needs? Should bioethics, which has traditionally stressed the primacy of individual autonomy, incorporate family caregivers' interests in addressing decision-making, especially in long-term care?

## What's Different Now: Just about Everything

Until recently, one of the foundational aims in bioethics was to uphold patients' right to be informed and to make their own decisions. The intention was to reduce "paternalism," the tendency of physicians to make some decisions for the good of their patients without their consent. While consent remains a cornerstone of bioethics, a sea change in caregiving needs and practice has given rise to a new set of ethical issues that concern caregivers themselves.

**Age.** The U.S. population is aging. A longer lifespan can mean many more productive and satisfying years, but it can also mean years of illness, frailty, and dependence.

**Care at Home.** Long-term care is often mistakenly assumed to be nursing home care, but in fact the majority of long-term care for older people is provided at home by family members.

**Gender.** Women, the traditional providers of family care, are now in the paid workforce in greater numbers. About 40% of all adult caregivers are men, but women continue to provide most of the day-to-day personal and household care. Half of family caregivers are employed full- or part-time. Caregivers who leave their

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## HIGHLIGHTS

- Most long-term care to the elderly is provided at home by family caregivers.
- Changes in demographics, workforce patterns, and health care economics have increased the need for—and complexity of—caregiving.
- Family caregivers are often marginalized by health care professionals and denied access to information that they may need to do a good job.
- Bioethics has traditionally focused on patients, but has recently explored the unmet needs of family caregivers.
- An understanding of the ethical concerns can help policymakers improve the quality of caregiving and the well-being of caregivers.

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## SUPPORT FOR FAMILY CAREGIVERS

*Several federal, state, and private programs offer financial and other assistance to family caregivers. Notably, however, few of these programs or proposals address the relationship between the family caregiver and health care providers.*

### Federal programs

The first federal program specifically to address family caregivers was the **National Family Caregiver Support Program** (NFCSP), established in the amendments to the Older Americans Act of 2000 and administered by the U.S. Administration on Aging. The program provides money to state Area Agencies on Aging to support information and referral services, respite services, counseling, and occasionally financial aid to family caregivers of people over the age of 60. Specific funds are earmarked for Native American tribes and grandparents raising grandchildren. The program was funded at \$153.4 million for 2008–2009, a decrease of \$2.7 million from the previous year. An additional \$6.3 million goes to Native American caregivers.

**Lifespan Respite Care Act**, which passed in both houses of Congress and was signed by President Bush in 2007, would provide competitive funds to states to develop coalitions of respite organizations. So far, the act has failed to obtain any appropriations.

Several proposals have been made for federal tax credits for family caregivers, generally at \$3,000, counting time off for caregiving toward Social Security credits, and other economic supports. None of these proposals has passed.

### State activities

Most of the public activity on family caregiving has taken place in state governments, with funds to provide information, referrals, and some in-home support, as well as caregiver assessment, counseling, and respite services. California, Pennsylvania, and New Jersey have been leaders in the breadth of services, innovation, and use of state dollars. The

New York State Family Caregiving Council advises the State Office for the Aging on ethics and policy. Some states have “cash and counseling” programs, financed by Medicaid waivers, which allow disabled people to choose either to use home health aides from agencies or to hire their own. They generally choose to hire—and pay—family members. Spouses cannot be paid workers. In addition, some states have modest tax credits for caregivers of about \$500.

### Employment programs

In 2004, California inaugurated a program to provide a percentage of income for family caregivers who take a leave from their jobs. Washington and New Jersey passed similar legislation. Some large corporations have “family-friendly” policies, including flex time, telecommuting, and referrals to employee assistance programs.

### Private funding

Private funding has created many caregiver services for specific populations—for example, caregivers of persons with Alzheimer disease or other dementia, cancer, multiple sclerosis, and other diseases. Sources of private funding include advocacy groups for particular illnesses and private foundations.

### “Virtual communities”

Many community agencies, government offices, and commercial interests have developed Web sites to provide information and support to family caregivers. A recent wave of “virtual communities” has stressed caregiver-to-caregiver support as well as online organizational tools to help friends and family sign up for certain support services.

jobs to provide care lose not only current income and access to health insurance, but also future Social Security benefits, retirement income, and job opportunities when caregiving ends—usually many years later.

**Technology.** Homes filled with all the trappings of a hospital room are subtly changed from havens of comfort and security to places of anxiety and sadness. Family caregivers are expected to provide the level of care that only a few decades ago was reserved for hospitals. But they are typically not trained or supervised.

**Family structure.** Family caregivers can be related by blood or marriage, but they can also be domestic partners or friends. Changes in family

structure have not diminished the basic instinct of people to care for others, but the health care, legal, and policy systems have not kept pace with these changes. It is often difficult for caregivers in non-traditional relationships to carry out their responsibilities. Such difficulties are compounded with family caregivers from minority or immigrant groups, who may have language barriers or religious practices that are unfamiliar to mainstream medical practitioners.

## The Cultures of Caregiving: Common Ground amid Conflict

Families and the U.S. health care system have

distinct cultures. Therefore a family member will approach the task of caring for a sick or an elderly person with a different set of priorities than a hired caregiver or a policymaker. Whatever their differences, families are characterized by relationships established by blood, marriage, or commitment. Family members' obligations to one another are moral, rather than legal. In contrast, the health care system is dominated by the culture of Western medicine, with its primary values of scientific evidence, oversight (legal, regulatory, and professional), efficiency, objectivity, confidentiality, technological solutions, and hierarchical organizations.

In our health care system, the patient, not the family caregiver, is legally entitled to receive services. (The exception is hospice, in which the family is the unit of care.) Policymakers' responsibilities include stewardship of scarce resources, which means balancing individual needs and community resources. They value cost-effective programs that serve populations, not case-by-case solutions, and expect individuals to draw upon personal or family resources as a first and perhaps only step.

Bioethics, with its traditional emphasis on individual patient autonomy, may have had an unintended consequence of relegating the family to a subsidiary, or even a negative, role. Controversial cases make news and material for bioethics commentary. They almost always involve family disputes (as in the Terry Schiavo case), a family's refusal to accept medical advice (as in the "Baby K" case, in which a parent insisted on treatment for an anencephalic newborn), or accusations of medical neglect and financial mismanagement (as in the Brooke Astor saga). Many cases that do not come to public attention do come before institutional ethics committees, where family members may be described as dysfunctional, selfish, and confrontational. Such families do exist, and others become confrontational when faced with what they perceive as failures to provide information, treatment decisions made by insurance companies, and discrimination of various kinds. Several writers in bioethics, such as Jeff Blustein, Hilde Lindemann, Martha Holstein, and James Nelson, have begun to shift the balance in bioethics so that family interests are weighed in concert with—not against—patient autonomy. A holistic view of a patient as person nearly always includes family.

Recognizing the differences in worldview between families and the health care system is the first step toward reducing conflict and finding com-

## CAREGIVING AT A GLANCE

- About 75–80% of all community long-term care is provided by family members. In 2002, 17% of frail older persons relied on a mix of family and paid care, and only 6.5% received paid care only.
- An estimated 30–38 million adult family caregivers provide on average 21 hours of care a week. This total does not include parents providing care for six million disabled children, or the more than one million children ages eight to 18 who provide substantial care to family members, or the two million grandparents raising grandchildren.
- The economic value of unpaid caregiving—what it would cost to replace family members' care—was \$350 billion in 2006, not including caregivers' out-of-pocket costs or lost income.

mon ground. An article in *Academic Medicine* in 2008 suggested that the first step in teaching "cultural competence" (in the traditional ethnic sense) to medical students is to teach that medicine has its own culture. "Physician, know thyself," the title of the article, could well be applied more broadly: "Family caregiver and policymaker, know thyself."

## An Ethical Framework for Public Policy

Most of the arguments for supporting family caregivers rest on economics: family caregiver assistance is essentially irreplaceable. Beyond the loving relationships embodied in family care, there is simply not enough money, nor are there enough workers, to replace family members as the broad base of the workforce. As the 2007 AARP issue brief on family caregiving puts it, "Adequate funding for family caregiver support will provide an excellent return on investment."

Ethical reasons are equally important. Public policy that supports family caregiving embodies the widely held view that families are intrinsically important because they give meaning and depth to fundamental human relationships. Furthermore, family caregiver support enhances patient care, a primary professional value.

Family caregivers' willingness to help does not remove all responsibility from policymakers, nor from health professionals, community organizations, and society in general. Family caregivers are not resources to be used until exhausted; they are true partners in care. Their mental and physical health and well-being are legitimate causes for con-

## RESOURCES

### Web sites

- [www.caregiver.org](http://www.caregiver.org) – Family Caregiver Alliance. Includes state-by-state policy analysis, data, and resources.
- [www.caregiving.org](http://www.caregiving.org) – National Alliance for Caregiving. Includes results of caregiver surveys on health, employment, costs of care, and other topics.

### Recent news

- Simona Covell, “Franchising: Taking Care of Business,” *Wall Street Journal*, March 17, 2008.
- Denise Grady, “Disease Brings Drastic Changes to Patients, and Stress to Family Members,” *New York Times*, December 26, 2007.
- Maggie Jackson, “Out-of-Pocket Elder Expenses Strain Caregivers’ Finances, Lives,” *Boston Globe*, December 16, 2007.
- Jane Gross, “Study Finds Higher Outlays for Caregivers of Older Relatives,” *New York Times*, November 19, 2007.
- Maggie Jackson, “A Modern Tapestry of Assistance,” *Boston Globe*, April 22, 2007.

### Further reading

- Thomas H. Dennison, “Changes in Nursing Home Care, 1996–2005: New York State,” February 2008. Issue brief available at [www.uhfnyc.org](http://www.uhfnyc.org).

- Carla Boutin-Foster, Jordan C. Foster, and Lyuba Konopas, “Physician, Know Thyself: The Professional Culture of Medicine as a Framework for Teaching Cultural Competence,” *Academic Medicine*, January 2008.
- AARP Public Policy Institute, “Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving,” June 2007. Issue brief available at <http://www.aarp.org/ppi>.
- Martha B. Holstein, “Long-Term Care, Feminism, and an Ethics of Solidarity,” in *Challenges of an Aging Society: Ethical Dilemmas, Political Issues*, ed. Rachel A. Pruchno and Michael A. Smyer, Johns Hopkins University Press, 2007.
- United Hospital Fund, Families and Health Care Project, “An Ethical Framework for New York State Policy Concerning Family Caregivers” and “New York State Policy Agenda for Family Caregivers,” November 2006. Reports available at [www.uhfnyc.org](http://www.uhfnyc.org).
- Carol Levine and Thomas H. Murray, eds., *The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy Makers*, Johns Hopkins University Press, 2004.



See legislation appendix.



See online-only campaign appendix at [www.thehastingscenter.org/briefing-book](http://www.thehastingscenter.org/briefing-book).

cern for bioethicists, public health officials, and medical professionals.

In ethical terms, the argument for supporting family caregivers can be made on the grounds of beneficence and justice. Beneficence, or respect for persons, may not raise any special concerns with regard to caregiving, unless there is a perception that a patient’s interests or needs are compromised by the needs and wishes of the caregiver. However, justice, or the fair distribution of goods and services, raises many unresolved questions in caregiving:

- With limited resources, which family caregivers should be targeted for support services?
- Should this support be based on income or vulnerability, or should it be more broadly available?
- When is it unreasonable to expect family care to continue?
- When children and teenagers provide care, should professionals set limits or intervene if parents or guardians don’t?
- Should caregivers of people with behavioral or cognitive problems and caregivers of people

with physical disabilities be treated equally?

- What should be the balance between supporting family caregivers and providing care to those without family?
- Does the principle of justice extend to gender divisions of labor within a family?

## Caregiving Policy Agenda

There are several ways that public policy can improve the quality of caregiving and the well-being of caregivers. Fostering better communication and coordination of care, as well as professional development, should lead the agenda.

**Communication.** Patients’ rights need to be balanced against caregivers’ needs for information. It can be extremely difficult for family members to get information about the medical condition of a relative for whom they provide care. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Privacy Rule implementing it in 2003 have caused consternation among many family caregivers. Although the law was not intended to change clinical practice or inhibit communi-

cation between providers and family caregivers, many health care providers have interpreted it as a warrant to withhold all information without a patient's written consent for fear of criminal liability and severe fines. Family caregivers, dependent on health care professionals to give them clear guidance and directions, now commonly hear, "I can't tell you because of HIPAA." The act has bolstered the view that families are nuisances and need not be part of decision-making. Public policy will have to address this issue and provide recourse for family caregivers who cannot obtain vital information for their caregiving responsibilities.

On the other hand, there are clear instances in which competent patients prefer to keep their medical information totally private, even from family caring for them. Discussion and resolution of these instances should be a fruitful exercise for clinical bioethics.

**Care coordination.** Many health care organizations are concerned about improving the coordination of care, especially during transitions between care settings. Poor communication and incomplete information have been shown to lead to medical errors, mainly involving medication management. Efforts to improve transitional care to date have focused on provider-to-provider communication, but family caregivers are typically left out of care planning, even though they are often the day-to-day care coordinators. Including family caregivers

goes against current practice; yet it is essential for quality care. Ways to involve family caregivers, assess their needs and limitations, and plan accordingly need to be on future policy agendas.

**Workforce development.** Another critical policy issue is to increase the number of professionals and paraprofessionals trained in geriatrics and willing to work in home settings. These people are in extremely short supply. The development of career ladders for home care aides and incentives for physicians and nurses to specialize in geriatrics will be needed to support future patients and family caregivers.

Family caregiving is not a just a "woman's issue," an aging issue, a health care issue, or a social service issue. It affects everyone at some point in their lives. Family caregiving is at the boundary of public and private realms, and policy-makers must tread carefully to preserve family values while crafting public solutions to caregiving needs.

The Institute of Medicine recognized this indispensable public-private partnership in an upcoming report, which states, "Ultimately, any plan for enabling informal caregivers and patients to become more capable members of the health care team is likely to require increased training along with greater support from and integration with the formal health care system." 