HOME SWEET HOSPITAL: 
THE NATURE AND LIMITS OF FAMILY RESPONSIBILITIES FOR HOME HEALTH CARE
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“As the eldest of five living children, I took responsibility because the others wouldn’t. It was a decision which cost me my health, my job and more than likely, my marriage.”
—Family caregiver, Georgia (1993)

“She is my mother; she is my responsibility; she is my blessing.”
—Family caregiver, Georgia (1993)

“Families need the opportunity to take responsibility for themselves.”

“A primary assumption that runs through this history [of long-term care] is that families, a euphemism for wives and daughters, would take primary responsibility for their disabled or impoverished elders.”
—Martha Holstein and Thomas Cole (1995)

“Most home health care agencies require there to be a ‘responsible person’ who can step in and personally provide or arrange for coverage if the aide is ill, detained...or irresponsible....The responsibility of the involved family member is nearly pervasive.”
—Nancy N. Dubler (1990)

“Responsibility” for the care of one’s family members is, according to these selected quotations, an opportunity that families need (and presumably lack), a task traditionally assigned to women, a personally costly obligation, a loving act, a total commitment. Responsibility is, variously, something to cherish, something to resent, something that is thrust upon one, or something that one tries to thrust upon others.

This essay is about concepts of family, private and public responsibility, and family capacity to provide care. Although informed by existing data and the work of pioneering researchers, it is not limited to what is quantitatively known or perhaps even knowable. And although it draws upon principles of biomedical ethics, it applies them in the arena

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of the family rather than the individual. The essay is intended to look broadly toward future home care policies and practices through the special lens of family or “informal” caregiving.

As the primary caregiver for my husband, who was totally disabled as a result of traumatic brain injury in an automobile accident nine years ago, my experiences also inform this essay. Personal experience is both a powerful reality check and a potential source of bias, but I use it as only one source of information. No individual’s or family’s story stands for the vast range of experience, both positive and negative, of caregiving in the United States today. Caregiving is experienced differently by, for example, the partner of a young man with AIDS; the husband of a 35-year-old mother of three with multiple sclerosis; the parent of an independent and resourceful 25-year-old with a spinal cord injury; the daughter of a frail elderly woman who lives alone but needs assistance in shopping, transportation, and financial management; the son of a woman in a hospice program who is dying of brain cancer; and the wife of a man with Alzheimer’s disease whose behavior is erratic and often hostile.

Although typically considered part of the private realm of intimate relationships, family caregiving is greatly influenced by the cultural, political and economic context of American society. Family caregiving is a traditional response to illness and disability, but it is not a static phenomenon. Some current problems have historical roots. For example, the burden of family care has always fallen especially on women, and most especially on poor women. The tension between paid work and family care felt so keenly today has existed in the United States at least since the nineteenth century.  

Currently both families and health care are changing dramatically. While in earlier eras, some individuals lived to great old ages, the average life expectancy was decades less than it is now. In 1850 just over 2 percent of the population was over the age of 65; now the percentage of people over 80 is growing rapidly. Although being old does not necessarily mean being frail or ill, there is an increase in diseases of aging, especially Alzheimer’s disease. Because physicians had few effective treatments until the antibiotic age, most people who suffered severe trauma or serious illness either got better or died. Nature put a limit on caregiving. In the twentieth century the advent of scientific medicine and the benefits of research, public health measures, better nutrition and safer jobs have enhanced and extended lives. Moreover, some recent successes of acute care medicine—for example, in the care of newborns and trauma patients—have also created a population of adults dependent to

1 Abel 1995.
2 Institute for Health and Aging at the University of California, San Francisco, 1996.