

CHAPTER 10



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Health Care Settings and Technologies

Timothy Diamond, a sociologist who spent several years working as a nursing aide in a variety of nursing homes, recounts the following experience:

Mary Ryan, like many others, spent all day in the day room, secured to her chair with a restraint vest. “How y’ doin’ today, Mary?” I once asked in passing.

She answered the question with a question. “Why do I have to sit here with this thing on?”

I responded automatically with a trained answer, “That’s so you won’t fall. You know that.”

“Oh, get away from me,” she reacted with disgust. “I don’t trust anyone in white anymore.”

Stunned by her rejection, and not completely confident of my own answer, I passed the question on to Beulah Fedders, the LPN [licensed practical nurse] in charge.

“Beulah, why does she have to wear that thing all the time?” Beulah accompanied her quick comeback with a chuckle. “That’s so they don’t have to hire any more of you.”

We snickered together at the humor of her explanation, but an explanation it was, and more penetrating than mine to Mary. It posed a relationship between technology and labor, and in that connection Beulah explained that the use of one could mitigate the need for the other. A different kind of answer to the same question was given during our orientation [by the home’s administrator]. “The restraint vests save on incidents. . . .”

Beulah’s answer was more accurate than “so you won’t fall” and “vests save on incidents,” because she connected them both to a common denominator—available labor. If no nursing assistant was there to be with Mary, to walk with her or anticipate her dizziness, and if she sat in the

chair without a restraint and without anyone to keep an eye on her, she might have fallen, thus generating an incident. Her restraint vest saved on incidents while it saved on labor costs. (Diamond, 1992: 182)

As this story suggests, a central dilemma of the American health care system is how to provide care in profit-driven institutions, as well as in nonprofit institutions that function within a broader, entrepreneurial system. In this chapter, we look at several settings where Americans obtain health care: hospitals, nursing homes, board and care homes, assisted living facilities, hospices, and family homes. We also consider a sociological analysis of the technologies that have become such a central part of care in these different settings.

The Hospital

The Premodern Hospital

The hospital as we know it is a modern invention. Before the twentieth century, almost all Americans, whether rich or poor, received their health care at home, from friends, relatives, and assorted health care providers. Because these providers used only a few small and portable tools, hospitals were unnecessary.

Some form of institution, however, was needed for those Americans too destitute to pay for care at home and for those who had no friends or relatives who could provide care. For these individuals, the only potential source of care was the **almshouse**. Here they—along with orphans, criminals, the disabled, the insane, and other public wards—would receive essentially custodial care. Conditions in almshouses generally were appalling. Inmates often had to share beds or sleep on the floor, and rats often outnumbered humans. Hunger was common and blankets and clothing scarce. These conditions, coupled with the lack of basic sanitation, made almshouses ideal breeding grounds for disease (Rosenberg, 1987: 31–32).

Wealthy Americans considered almshouse conditions quite acceptable for those they regarded as lazy, insolent, alcoholic, promiscuous, or incurable (categories they believed included all nonwhites). By the end of the eighteenth century, however, wealthy Americans began to view these conditions as unacceptable for those they considered the “deserving” poor—the respectable widow, the worker crippled by accident, the sailor struck by illness far from home. With such individuals in mind, philanthropists decided to develop a new form of institution, the hospital, devoted solely or primarily to **inpatient** care of the “deserving” sick. These hospitals would function as nonprofit, or **voluntary, hospitals**, so named because they reflected a spirit of voluntarism, or charity, rather than a profit motive. Such institutions would protect the morally worthy poor from the degradations of living in an almshouse and associating with the morally unworthy poor.

The first two American hospitals were founded in the late eighteenth century, and a trickle of others appeared during the first half of the nineteenth century. Reflecting their origins in social rather than medical concerns, these early hospitals accepted only patients certified as deserving. Hospitals often required those seeking care to provide letters of reference from their employers or ministers (Rosenberg, 1987: 19–20). In addition, hospitals generally refused patients with chronic, contagious, or mental illnesses, making exceptions only rarely for the few who could pay for care.

Not surprisingly, given the essentially moral concerns of hospital founders, doctors played only a small role in hospital care and an even smaller role in hospital administration. Instead, hospitals relied on lay administrators or trustees, appointed more for their social status and charitable donations than for their medical knowledge (Rosenberg, 1987: 47–68). From the beginning, though, hospitals partially justified their existence by pointing to their role in medical education, and the few elite doctors who worked in hospitals derived both status and financial profit from that association.

Early nineteenth-century hospitals differed dramatically from modern hospitals. Until after the Civil War, the large ward remained the center of all hospital activity. Admissions, diagnostic examinations, surgical operations, the last moans of the dying, and ministrations for the dead all occurred on the ward in full view of other patients and staff.

Although conditions in hospitals were better than in almshouses, they remained unpleasant. Throughout most of the nineteenth century, hospitals were chaotic and dirty places. According to historian Charles Rosenberg:

Nurses were often absent from assigned wards and servants insolent or evasive. Chamber pots [used for urinating and defecating] remained unemptied for hours under wooden bedsteads, and mattresses were still made of coarse straw packed tightly inside rough ticking. Vermin continued to be almost a condition of life among the poor and working people who populated the hospital's beds, and lice, bedbugs, flies, and even rats were tenacious realities of hospital life. (1987: 287)

These conditions, plus the severe limitations of contemporary medicine, kept **mortality** rates high and taught the public to associate hospitals with death rather than treatment.

Hospitals functioned as **total institutions** (described in Chapter 7), in which patients traded individual rights for health care (Rosenberg, 1987: 34–46). Hospital rules regulated patients' every hour, including mandating work schedules for all who were physically capable. Patients who did not follow the rules could find themselves thrown into punishment cells or frigid showers.

Engraving from *Harper's Weekly*, 1860. Museum of the City of New York. Reprinted by permission.



A ward overrun by rats in New York's Bellevue Hospital. This woman's baby was eaten by rats.

Beginnings of the Modern Hospital

Given the rigors of hospital life, the **stigma** of charity that accompanied hospital care, and the association of hospitals with death, early nineteenth-century Americans entered hospitals only as a last resort. The Civil War, however, began to change this (Rosenberg, 1987: 98–99). During the war, the need to care for sick and wounded soldiers exposed middle- and upper-class Americans to hospital care for the first time, as both patients and health care workers. Of necessity, during the course of the war, hospital organization and care improved, at least for the better-financed Union Army. These changes demonstrated that hospitals need not be either deadly or dehumanizing.

Following the war, widespread adoption of new ideas about the dangers of germs and the importance of cleanliness helped to make hospitals safer and more pleasant, as did technological changes including the development of disposable gauze and cheaper linens, which made cleanliness feasible (Rosenberg, 1987: 122–141). Concurrently, demographic changes made hospitals more necessary. The tremendous spurt in immigration, the growth of cities, and the resulting overcrowding and dire poverty made it impossible for many Americans to recuperate from serious illnesses or injuries at home. Meanwhile, the growth of industry and technology fostered accidental injuries, and poor and crowded living conditions bred contagious diseases that required hospital treatment. Medical changes, too, made hospital care more necessary, as doctors came to value the technologies and germ-free surgical conditions available only in hospitals (Rosenberg, 1987: 149).

Yet affluent Americans remained generally unwilling to tolerate the conditions on even the cleanest hospital wards. As a result, and to compete with the **for-profit, private hospitals** that began appearing during the second half of the nineteenth century, voluntary hospitals developed a class-based system of services (Rosenberg, 1987: 293–294). Those who could pay for private accommodations received better heating and furnishings, exemption from many hospital rules, and privileges such as more anesthesia during operations. In addition, as hospitals increasingly became involved in medical education, private patients retained the right to treatment by their private doctors, while charity patients endured treatment by inexperienced medical students or **residents**. Through these changes, voluntary hospitals began to lose their ethos of service and became increasingly like their for-profit competitors.

The Rise of the Modern Hospital

By the early twentieth century, the hospital as we now know it had become an important American institution and a major site for medical education and research. In the 50 years between 1873 and 1923, the number of hospitals increased from 178 to almost 5,000 (Rosenberg, 1987: 341). These new hospitals also included **government hospitals**, established to provide services to those groups—the insane, the chronically ill, and the “undeserving poor”—that voluntary hospitals considered unworthy and for-profit hospitals considered money losers. However, African Americans still could obtain care only in a few segregated, poorly staffed, and poorly funded wards and hospitals; in municipal hospitals where medical students and residents could learn skills by practicing on African American patients; and sometimes in other hospitals for emergency care (R. Stevens, 1989: 137).

This hospital building boom reinforced the class division within voluntary hospitals. According to Rosemary Stevens (1989: 112), the voluntary hospital of the early twentieth century “was like a multiclass hotel or ship, offering different facilities for different prices. The grade of semiprivate patients, tucked in between private patients and the wards, seemed the logical development of a new ‘cabin class’ between ‘first class’ and ‘steerage.’” Thus by the 1920s, voluntary hospitals had abandoned much of their original charitable mission and become big businesses. As such, they had come to reflect the American ideology that individuals should get only what they pay for, in health care as in other areas (R. Stevens, 1989: 112).

By this time, surgical admissions to hospitals far surpassed medical admissions (Rosenberg, 1987: 150). Most patients went to a hospital to have their tonsils, adenoids, or appendixes removed; their babies delivered; or their injuries treated (R. Stevens, 1989: 106). The emphasis on technology as a defining aspect of modern hospitals further reinforced hospitals’ tendency to focus on the care of **acute** rather than **chronic illness**.

This emphasis, coupled with hospitals' desire to maintain their image as proper middle-class institutions, created problems in the years following World War I, when hospitals proved extremely loath to deal with the chronic health problems of veterans (R. Stevens, 1989: 126–128). Many veterans were poor and suffered from crippling or disfiguring problems not amenable to the acute or surgical care that hospitals emphasized. Yet Americans generally believed that veterans had earned the right to health care. As a result, in 1921, Congress voted to establish a national system of **veterans hospitals**.

By initiating a federal system of veterans hospitals, the government gained a chance to set national norms for health care, overriding local norms of racial segregation (R. Stevens, 1989). Instead, however, the federal government bowed to local political pressure and decided to allow African American veterans to use veterans hospitals only in emergencies or in segregated wards. These policies did not change until after the civil rights struggles of the 1960s (R. Stevens, 1989: 222).

The number of hospitals increased dramatically following passage of the 1946 Hill-Burton Act, which provided funding for hospital construction. During the next 14 years, 707 voluntary hospitals and 475 state and local hospitals were built, and the rate of hospital admissions increased substantially. As with the development of the veterans hospital system, however, the federal government did not use this opportunity to develop a rational and national health care system. Instead of tying funding to regional health needs, the government allowed hospitals to pursue their private financial interests: focusing on acute rather than chronic illness; discouraging non-paying patients; reinforcing local norms of racial segregation; and buying expensive, esoteric technology even if it duplicated that owned by nearby hospitals (R. Stevens, 1989: 200–232).

Hospitals Today

Federal subsidies for hospitals expanded substantially following the implementation in 1965 of **Medicaid** and **Medicare**. These plans dramatically increased the profits available to hospitals and spurred the merger of hospitals into for-profit and voluntary hospital chains (such as Humana and Sisters of Charity, respectively). Chains controlled 45 percent of U.S. hospitals in 2000 (American Hospital Association, 2002).

As hospital profits grew, so did costs to the federal government via Medicaid and Medicare. As a result, the government for the first time developed a vested interest in controlling hospital costs. Ironically, the resulting price-control programs (described in Chapter 8) such as **diagnosis-related groups (DRGs)** have pressured hospitals to pay more attention to the bottom line and therefore encouraged voluntary hospitals, which remain the center of the hospital system, to act more like for-profit hospitals (R. Stevens, 1989: 305).

More recent cost-containment programs have especially squeezed funding for public hospitals. Under any circumstances, it is difficult for public

hospitals to make ends meet, because about one-third of their patients cannot pay their hospital bills (Andrulis et al., 1996). Until recently, however, public hospitals could subsidize these patients through “disproportionate share funds” given by each state to hospitals that serve a disproportionate share of poor persons. In addition, public hospitals could subsidize nonpaying patients using grants received from the federal government for training medical residents. In the last few years, however, states instead have given some of their disproportionate share funds to **managed care organizations (MCOs)** in exchange for providing insurance coverage to Medicaid recipients. Meanwhile, the federal government has cut funding for medical residencies as a means of decreasing the oversupply of physicians. Taken in combination, these two changes have reduced budgets substantially at public hospitals, resulting in cutbacks, hospital closings, and, particularly, the closing of emergency rooms (which typically lose money for hospitals).

Concern about costs and profits also has affected the mix of services offered by hospitals (R. Stevens, 1989: 334). Hoping to increase profits by offering services that patients would pay for out of pocket (avoiding managed care restrictions altogether), a growing proportion of hospitals now offer alternative therapies such as yoga, meditation, and massage (Abelson and Brown, 2002). Similarly, because insurers (including Medicare under the DRG system) typically pay only preset amounts for inpatient surgery but give hospitals more leeway in setting prices for outpatient surgery (that is, surgery given without formally admitting the patient to the hospital or requiring an overnight stay), hospitals now offer **outpatient** surgery whenever technically feasible. As a result, outpatient surgery increased from 20 percent of all hospital surgeries in 1981 to 60 percent in 1996 (American Hospital Association, 1998). At the same time, the competitive market environment has encouraged hospitals to offer new, technologically intensive treatments even if other nearby hospitals already do so. The result has been a proliferation of technology, as Table 10.1 demonstrates. Similarly, intensive care units, almost unknown in the 1960s, were found in 66 percent of hospitals by 1998 (American Hospital Association, 1998: 151). Because of these changes, hospitals now treat an older and sicker mix of patients, most of whom suffer from the acute complications of chronic illnesses.

Conversely, as hospitals have shifted toward providing more intensive care for middle-class Americans, some (especially government hospitals) have moved, if unwillingly, toward becoming **primary care** providers for the poor. Patients who have neither health insurance nor money to pay for care will sometimes turn to hospital outpatient clinics and emergency rooms not only for treatment of acute problems, such as gunshot wounds, but also for chronic problems, such as backaches. This **emergency room abuse**, as it is defined by hospitals, aggravates exhausted medical staff and worries hospital administrators concerned about budgets. In turn, it has fostered **patient dumping**, in which voluntary and for-profit hospitals place patients, sometimes in serious medical distress, in ambulances and deliver

Table 10.1 *Proportion of U.S. Nonfederal Hospitals Owning Various Technologies, 1984 and 1998*

TECHNOLOGY	1984 (%)	1998 (%)
Angioplasty	0	21
CT scanner	48	76
Magnetic resonance imaging (MRI)	3	44
Open-heart surgery facilities	12	18

Source: American Hospital Association (1998: 151–160).

them to the emergency rooms of government hospitals—often without informing either the patient or the receiving hospital beforehand.

In response to this problem, Congress in 1985 passed the Combined Omnibus Budget Reconciliation Act (COBRA), which made it illegal for hospitals to transfer physically unstable patients. This law, however, has not ended the problem. Between 1997 and 1999, federal investigators confirmed reports implicating 500 U.S. hospitals in patient dumping (Blalock and Wolfe, 2001). For-profit hospitals were 1.7 times more likely to dump patients than were nonprofit hospitals. These numbers undoubtedly underestimate such incidents because the groups most likely to be dumped—the poor and the powerless—are the groups least likely to file complaints.

The Hospital-Patient Experience

For many patients, a hospital stay is now a matter of only a few hours or days. For example, before World War II women typically stayed in the hospital for two to three weeks following childbirth; they now stay an average of 2.5 days. Similarly, the average stay for hospital patients overall was 4.9 days in 2002, compared with 12.5 days in 1923 (DeFrances and Hall, 2004; Starr, 1982: 158).

Certainly hospitals no longer terrify and endanger patients as they did in the nineteenth century. Yet, a hospital stay often remains alienating and frightening. The bureaucratic nature and large size of modern hospitals, coupled with the highly technological nature of hospital care, often means that the patient as individual person, rather than just a diseased body, gets lost.

The reasons behind this are obvious and, to some extent, unavoidable. First, increasingly patients enter hospitals needing emergency care. Often, health care workers must respond immediately to their needs and have no

time to talk with them to ascertain their preferences—which many are physically incapable of expressing in any case. Second, the highly technical nature of hospital care encourages staff to focus on the machines and the data these machines produce rather than on the patient as a whole person. In the modern obstetric ward, for example, workers often focus much of their attention on the electronic fetal monitor rather than on the laboring woman (E. Martin, 1987: 142–146). Third, as we will see in Chapter 11, medical training encourages doctors to focus on biological issues much more than on patients' psychological or social needs. At the same time, short stays make it less likely that patients will develop a personal relationship with either hospital staff or other patients. Fourth, as large institutions necessarily concerned with economic profitability or at least stability, hospitals cannot afford to provide individualized care. Instead, hospitals rely on routines and schedules for efficiency. These routines and schedules leave little leeway for individual needs or desires, resulting in such ironies as nurses awakening patients from needed sleep to take their temperature or blood pressure.

Public dissatisfaction with the often dehumanizing nature of hospital care, combined with market pressures, has led hospitals to make at least superficial changes in care. For example, since the early 1990s, most U.S. hospitals have offered people who consider the standard hospital labor and delivery rooms emotionally and physically uncomfortable the option of using a “birthing room,” which offers a more home-like environment. Critics, however, note that these rooms are still filled with medical technologies—such as intravenous pumps, fetal monitors, and so on—whose very presence makes their use more likely.

Nursing Homes

From the start, American hospitals focused on caring for acutely ill persons and assumed that families would care for chronically ill persons. During the course of the twentieth century, however, average life expectancy increased; families grew smaller, more geographically dispersed, and less stable; and women less often worked at home. As a result, more and more Americans needed to seek long-term care from strangers, and **nursing homes**—facilities that primarily provide nursing and custodial care to groups of individuals over a long period of time—became part of the American landscape.

The number of nursing homes has tripled since 1980. Currently there are about 15,000 skilled nursing homes in the United States, with about two-thirds run for profit (U.S. Bureau of the Census, 2004). Skilled nursing homes accept only patients under a doctor's care and provide both medical and trained nursing care. In addition, the many intermediate care nursing homes in the country provide bed and board, but only less-intensive health care.

Who Uses Nursing Homes?

Researchers project that 39 percent of Americans who are now 80 will have to enter a nursing home before they die (Murtaugh et al., 1997: 213). As of 2005, about 1.6 million Americans live in nursing homes. Women comprise 72 percent of these nursing-home residents—not just because women live longer, and thus more often eventually need assistance, but because women less often have a surviving spouse who can and will care for them. Although illness and disability can force individuals into nursing homes at any age, nursing-home residents overwhelmingly are elderly: 78 percent are age 75 or older, and only 10 percent are under age 65.

On average, current nursing-home residents are sicker than were residents a decade ago. This change stems from the economic incentives built into DRGs, which have encouraged hospitals to discharge patients “sicker and quicker”—physically stable but still ill—once their bills and lengths of stay exceed the limits set by Medicare for hospital coverage. Those patients who cannot care for themselves at home often are discharged directly to nursing homes.

Although some people stay in nursing homes for only a few weeks, others stay for several years. A survey of nursing-home residents conducted by federal researchers in 1995 found that the average length of stay for all persons over age 65 was 2.3 years (Dey, 1997).

Financing Nursing-Home Care

As of 2005, nursing-home care costs at least \$40,000 per person per year, and more than \$100,000 in expensive parts of the country. Few Americans have private insurance that will pay these costs. Although individuals can buy **long-term care insurance** to cover the costs of nursing or custodial care, its steep price and limited benefits make it unaffordable for most. Nor can most Americans rely on Medicare to finance nursing-home care, because Medicare pays only for skilled (rather than custodial) nursing care and only for the first 150 days.

In the absence of comprehensive coverage for long-term care, nursing-home residents rapidly slide toward poverty. Those who survive long enough eventually reach the limits of any private or Medicare coverage. They may then obtain Medicaid or other public aid, but only after selling all their assets (minus their houses if they are married) and spending all their savings (minus the cost of burial expenses and minimum living expenses for their spouses).

As of 2003, Medicare covers 12 percent of all U.S. nursing-home bills, and Medicaid covers 46 percent. These programs pay the homes directly, giving residents only a small monthly stipend from which to purchase all personal items, such as cigarettes, gifts, greeting cards, phone calls, or clothes. Moreover, because Medicaid will pay only a certain amount per month for care, as residents progress from Medicare to Medicaid, nursing homes often move residents to cheaper and lower-quality facilities either within a given home or in another home.

Working in Nursing Homes

Nursing-home care is extremely labor intensive. To provide this care, nursing homes rely almost solely on **nursing assistants** (who often have no training) augmented by **licensed practical nurses** (who have completed approximately one year of classroom and clinical training).

Nationally, nursing assistants (half of whom work in nursing homes and one-quarter in hospitals) form one of the largest and fastest-growing health care occupations (Bureau of Labor Statistics, 2004). Almost all are women, and most are nonwhite. Many come from Africa, Asia, or Latin America and are not native English speakers. Often they obtain their airfare to the United States as loans from nursing agencies in exchange for signing contracts obliging them to work for those agencies until they have repaid their debt (Diamond, 1992). These contracts leave them vulnerable to unscrupulous employers because, as essentially bonded laborers, these women have no legal grounds for requesting better wages or working conditions.

In some states, nursing assistants must complete a seventy-five-hour course and pass a state examination before seeking employment, but in others nursing assistants need neither training nor experience. In 2002 those who worked in nursing homes earned an average of \$32,220, in many cases by working two jobs or double shifts (Bureau of Labor Statistics, 2004; Diamond, 1992).

To understand the life of nursing-home residents and the nursing assistants who care for them, sociologist Timothy Diamond (1992) became certified as a nursing assistant and worked for several years in a variety of nursing homes. He soon concluded that the core of working as a nursing assistant is caregiving, but that those who train nursing assistants do not recognize this basic fact. Instead, his instructors taught him to recite biological and anatomical terms, measure vital signs, and perform simple medical procedures. Instructors divorced these skills from any social context or any sense that their patients were people rather than inanimate objects. Moreover, the skills Diamond most needed he was never taught, such as exactly how do you clean an adult who has soiled a diaper in a manner that preserves the individual's sense of dignity? Only by labeling this caregiving as mere physical labor could those who hire nursing assistants label them "unskilled" and treat them so poorly.

Life in Nursing Homes

Diamond's research underlines how the fates of nursing assistants and nursing-home residents intertwine and how even in the best nursing homes, the economics of a profit-driven system produce often intolerable conditions for both. According to Diamond, within nursing homes

caregiving becomes something that is bought and sold. This process involves both ownership and the construction of goods and services that can be measured and priced so that a bottom line can be brought into being. It entails the enforcement of certain power relations and means of production so that those who live

in nursing homes and those who tend to them can be made into commodities and cost-accountable units. (1992: 172)

In this process of **commodification**, or turning people into commodities, “Mrs. Walsh in Bed 3” becomes simply “Bed 3.” To keep down the price of this “commodity,” only the most expensive homes provide private rooms or separate areas for residents who are dying, incontinent, smelly, or insane. Privacy, then, also becomes a commodity, which few residents can afford.

Nursing assistants, meanwhile, become budgeted expenses, which homes try to keep to an absolute minimum. According to federal researchers, 91 percent of nursing homes have insufficient staff to provide even the minimum standard of care needed (Pear, 2002c). As a result, patients across the country experience bedsores, malnutrition, pneumonia, and other avoidable health problems. To justify these low staffing levels, nursing-home administrators and owners narrowly define the caregiving that assistants provide and residents need. For example, managers may hire only enough assistants to hurriedly spoon-feed residents rather than enough to allow assistants to chat with residents while feeding them or to help residents retain their dignity by feeding themselves. Similarly, managers can keep residents drugged, strapped to chairs, on a strictly regimented schedule, and in a single central room during the day so that a few assistants can supervise many residents; nationally representative studies have estimated that on any given day, nursing homes physically restrain between 20 and 38 percent of residents (Castle and Mor, 1998). The same logic frequently leads nursing homes to reward aides who work quickly and efficiently (even if the aides must bully or coerce patients to do so) and to penalize aides who spend the time needed to offer true caring (Foner, 1994).

Although all these problems also can occur in nonprofit nursing homes, a review of data collected by federal regulators on all U.S. nursing homes found that both quality of life and quality of nursing and medical care were significantly worse in for-profit homes (Harrington et al., 2001). One reason for this is that within the profit-driven system, managers constantly stress to staff that *providing* care is less important than *documenting* care. As a sign proclaimed in one nursing home where Diamond worked, “If it’s not charted, it didn’t happen.” For example, state regulations where Diamond worked required homes to serve residents certain “units of nutrition” each day. Consequently, each day Diamond collected the cards placed on residents’ food trays that named the foods and their nutritional content. Every few months, state regulators would inspect the cards and certify that the homes met state nutritional requirements. Yet these cards bore little relationship to reality, for the appetizing-sounding names given to the foods rarely matched the actual appearance or taste of the food. Nor did the cards note if a resident refused to eat a food because it was cold, tasteless, or too hastily served. Similarly, sanitation regulations required homes to shower residents regularly but did not require that the showers be warm. Nor did they require the homes to hire enough nursing

assistants so that residents who used diapers could be cleaned as soon as needed, or so that residents could get the help they needed in using the toilet and avoid the indignity and discomfort of diapers.

Problems such as these led Diamond to conclude:

It made a certain kind of sense . . . that in the schooling and textbooks there had been no vocabulary of caring. There was no place for it in the records. Words that concerned how to be gentle with Arthur, firm with Anna, delicate with Grace; how to mourn with Elizabeth and mourn for Frances; how to deal with death and dying, loneliness and screaming; how to wait in responding to someone else's slow pace—these constituted much of the work as it went along, but nothing of the job. In the documentation there was nothing relational, no shadow of the passion, only a prescribed set of tasks a doer gave to a receiver. (1992: 163)

Board and Care Homes

Nursing homes were developed to provide long-term care to individuals who did not need hospital care but who required too much medical or nursing care to live on their own. Other individuals, however, require neither medical nor nursing care but do need assistance in routine daily tasks such as bathing, dressing, and meal preparation. This group has grown substantially in recent years, due partly to the aging of the American population, the increasing survival rates of severely disabled infants, and **deinstitutionalization** (described in Chapter 7). Recognition of this market has stimulated the growth since the mid-1980s of **board and care homes**—residential facilities, typically based in private homes with shared baths, that provide assistance in daily living but neither nursing nor medical care. Although some homes serve as many as twenty-five clients, many more are family homes with as few as one client.

Board and care homes remain largely unregulated, and licensure is not required in all states. As a result, only minimal data on these homes are available. The absence of regulation, coupled with the dependence of residents and the emphasis on profits, increases the potential for physical as well as emotional abuse in board and care homes.

Assisted Living Facilities

Like nursing homes and board and care homes, **assisted living facilities** have experienced explosive growth in recent years. Assisted living facilities provide fewer medical and nursing services than do nursing homes but more than do board and care homes, and they offer greater independence and privacy than either of these. More than 500,000 individuals, with an average age of 84, now live in these facilities, the number of which increased 30 percent between 1998 and 2000 alone (*Consumer Reports*, 2001).

Unlike nursing homes, which typically consist of wards, assisted living facilities typically consist of small private or semiprivate apartments. Like nursing homes, they provide help with basic tasks of daily living (such as meal preparation and housecleaning) and with routine nursing tasks (such as administering medications). These facilities also typically offer some medical care, although most states forbid them from caring for persons who have unstable medical conditions or require around-the-clock nursing. In addition, assisted living facilities offer local transportation and social activities for those who are reasonably healthy as well as the opportunity to transfer to nearby units with higher levels of care for those whose health deteriorates.

The promise of assisted living facilities is that they will allow residents to “age in place.” In fact, however, residents stay an average of less than three years, with most who leave moving to nursing homes (Chapin and Dobbs-Keeper, 2001).

Assisted living facilities were first developed in response to market demand from upper-income persons, who remain their main clientele. They have grown in number as states increasingly have looked to such facilities as a means of reducing the costs they pay for nursing-home care, which account for about 35 percent of all state Medicaid expenditures. As of 2001, thirty-seven states theoretically cover the costs of assisted living facilities—sometimes more than \$4,000 per month—for those who otherwise would be placed in nursing homes at state expense (*Consumer Reports*, 2001). However, obtaining such funding is difficult, and most assisted living residents pay out of pocket.

Hospices

Origins of Hospice

Whereas nursing homes emerged to serve the needs for long-term care not met by hospitals, and board and care homes arose to serve the needs not met by nursing homes, **hospices** emerged out of growing public recognition that none of these options provided appropriate care for the dying.

Only in the last few decades has institutional care for the dying become a public issue. At the beginning of the twentieth century, few individuals experienced a long period during which they were known to be dying. Instead, most succumbed quickly to illnesses such as pneumonia, influenza, tuberculosis, or acute intestinal infections, dying at home and at relatively young ages. Now, however, most Americans live long enough to die from chronic rather than acute illnesses. In addition, as doctors and scientists have developed techniques for detecting illnesses in their earliest stages, they now more often identify individuals as having a fatal illness long before those individuals actually die. Thus, dealing with the dying is to some extent a uniquely modern problem and certainly has taken on a uniquely modern aspect.

Although modern medical care has proved lifesaving for many, its ability to extend life can turn from a blessing to a curse for those who are dying

(as this chapter's ethical debate on the right to die, Box 10.1, discusses in more detail). For various reasons, including the **technological imperative** underlying medical care, legal concerns about restricting care, and financial incentives that encourage the use of highly invasive treatments, thousands of Americans each year receive intensive, painful, and tremendously expensive medical care that offers only a small hope of either restoring their quality of life or extending their lives. In nursing homes, on the other hand, the emphasis on profit making and cost cutting often results in dying persons receiving only minimal and depersonalized custodial care.

This lack of appropriate care for the dying led to the development of the hospice movement. The first modern hospice, St. Christopher's, was founded in England in 1968 by Dr. Cicely Saunders, specifically to address the needs of the dying and to provide an alternative to the often alienating and dehumanizing experience of hospital death (Mor, 1987). The hospice admitted only patients expected to die within six months and offered only palliative care (designed to reduce pain and discomfort) rather than treatment or mechanical life supports. The hospice provided care both in St. Christopher's and in patients' homes.

The hospice movement received a substantial boost with the publication of Elizabeth Kübler-Ross's book *On Death and Dying* (1969), which helped to make dying an acceptable topic for public discussion. The first American hospice, which closely resembled St. Christopher's, opened five years later in New Haven, Connecticut. Other hospices soon followed, emerging from grassroots organizations of religious workers, health care workers, and community activists seeking alternatives to hospitals and nursing homes. Public support for hospices was so immediate and so great that in 1982, only eight years after the first American hospice opened, Congress (hoping that supporting hospices would both reduce health care costs and garner votes) approved covering hospice care under Medicare (Mor, 1987: 12–14).

The Hospice Philosophy

The early hospice philosophy differed markedly from mainstream medical philosophy (Abel, 1986; Finn Paradis and Cummings, 1986; Mor, 1987). First, the hospice philosophy asserted that patients should participate in their own care and control as much as possible the process and nature of their dying. Hospices strove to give clients choices over everything from what they ate to where they would die. Most significantly, hospices allowed residents to decide when to receive pain medications, how much, and what kinds. To eliminate pain from the experience of dying, hospices used whatever drugs would work, including opiates such as heroin. In contrast, nursing-home staff do not have the expertise to prescribe or supervise the drugs that dying patients need, and hospital staff often oppose using addictive drugs because their commitment to healing makes it difficult for them to acknowledge that certain patients are dying and therefore cannot be harmed by addictive drugs.

Box 10.1 ***Ethical Debate: A Right to Die?***

In 1983, 26-year-old Elizabeth Bouvia, suffering near-total paralysis from cerebral palsy and near-constant pain from arthritis, presented herself for admission to Riverside General Hospital. In years past, and despite her physical problems, Bouvia had earned a degree in social work, married, and lived independently. However, after her efforts to have children failed, her husband left her, and the state stopped paying for her special transportation needs, she lost interest in living. Her purpose in coming to the hospital, she told the hospital staff soon after her admission, was to obtain basic nursing care and painkilling medication while starving herself to death, cutting short what might otherwise have been a normal life span. The hospital's doctors took her case to court and won the right to force feed her, on the grounds that although individuals have the right to commit suicide they cannot force health care workers to commit **passive euthanasia** (i.e., to allow patients to die through inaction).

In 1990, Janet Adkins, 54 years old and suffering from Alzheimer's disease, killed herself with the assistance of Dr. Jack Kevorkian. A pathologist, Kevorkian had designed a machine that allowed people with severe disabilities to give themselves a fatal dose of sodium pentothal and potassium in the privacy and freedom of their homes. Over the next decade, Kevorkian provided doctor-assisted euthanasia to more than 100 people. He has been charged with murder multiple times, but was first convicted in 1999, after administering a lethal injection himself, rather

than having his client do so, and sending a videotape of the death to CBS-TV.

In the Netherlands, meanwhile, doctors legally can practice active voluntary euthanasia so long as they follow established guidelines. Those guidelines restrict active euthanasia, in which a doctor ends a patient's life through action rather than inaction, to cases in which mentally competent but incurably ill individuals suffering intolerable and unrelievable pain authorize their doctors in writing to give them a lethal injection. According to several national surveys conducted over the past 15 years, at least two-thirds of Americans believe that terminally ill people have a right to die, and a right to their doctors' assistance (*Contexts*, 2004). As of 2005, only one state, Oregon, has adopted a legal statute permitting doctor-assisted suicide. (The Bush administration contested the legality of that statute, but the Supreme Court issued a decision upholding it in 2006.) Even in states that lack such laws, however, some U.S. doctors engage in euthanasia or physician-assisted suicide; in a nationwide random survey of oncologists (physicians who treat cancer), 10.7 percent reported having done so at some point in their careers (Emanuel et al., 1998).

Those who support a "right to die" argue that competent adults have the right to make decisions for themselves, including the ultimate decision of dying. They argue that death sometimes can be a rational choice and that forcing individuals to suffer extreme physical or mental anguish is unwarranted cruelty.

If we accept that death can be a rational choice, then harder questions follow. Why is it rational only if one's condition is terminal? Doesn't it make even more sense to end the life of someone like Elizabeth Bouvia, whose agonies may continue for another 50 years, than to end the life of someone who will die soon regardless? Why should this choice be forbidden to individuals simply because they cannot, either physically or emotionally, carry it out themselves? And why should we allow individuals to choose death only through passive euthanasia, leaving them to languish in pain while awaiting death, if instead they could be killed quickly and painlessly?

Opponents of this view argue that the duty to preserve life overrides any other values and that euthanasia is merely a nice word for suicide or murder. They question whether Elizabeth Bouvia would still want to kill herself if she once more had the resources she needs to live independently, and they wonder whether euthanasia is merely an easy way out for a society that wants to avoid responsibility for relieving the burdens imposed by illness and disability. Opponents who have studied the Netherlands suggest that doctors there in fact do not always follow the legal guidelines, but instead sometimes end patients' lives without their consent and without first attempting to make the patients' lives worth living (Hendlin, Rutenfrans, and Zylicz, 1997). In addition, opponents question whether acceptance of euthanasia in the Netherlands explains why there are fewer hospices in the Netherlands

than elsewhere in Europe and why Dutch doctors receive relatively little training in pain relief.

In sum, the use of euthanasia, whether active or passive, raises numerous difficult questions: What are the consequences of, in effect, declaring it reasonable for disabled people to choose death? What pressures does this place on individuals to end their own lives rather than burdening others? What responsibilities does this remove from society to make these individuals' lives less burdensome? Finally, given that social factors, such as age, gender, and social class, affect our perceptions of individuals' worth, how do we ensure that health care workers and courts will not be more willing to grant a right to die to those who belong to socially disvalued groups?

Sociological Questions

1. What social views and values about medicine, society, and the body are reflected in this debate? Whose views are these?
2. Which social groups are in conflict over this issue? Whose interests are served by the different sides of this issue?
3. Which of these groups has more power to enforce its view? What kinds of power do they have?
4. What are the intended consequences of the various policies under consideration? What are the unintended social, economic, political, and health consequences of these policies?

Second, the hospice philosophy foreswore regimentation and stressed the importance of integrating hospice care into clients' everyday lives rather than integrating clients into hospice routines. Where possible, hospices would offer services in clients' homes. For those who needed care in the hospice, the hospice would offer a home-like environment, without the regulations regarding schedules, visitors, food, clothing, and so on that rule life in hospitals and nursing homes.

Third, the hospice philosophy emphasized a true team approach. Because hospices provided neither diagnosis nor treatment, doctors could claim little special expertise (Abel, 1986). As a result, within hospices, doctors had little more importance or influence than did social workers, nurses, ministers, psychotherapists, nutritionists, and others. Hospices explicitly worked to minimize the authority of doctors and to increase the role and status of nonprofessional volunteers.

Fourth, hospices focused not only on the dying person but also on his or her friends and relatives. Hospices attempted to involve these others in the process of dying and to meet their social and psychological needs. As a result, hospice care did not end with the client's death but extended to bereavement counseling for survivors.

Finally, hospices viewed dying "as a natural event rather than as technological failure" (Abel, 1986: 71). Workers viewed dying as an important phase of life, suitable for and worthy of open discussion. Neither the dying process nor the disease was to be hidden.

The Cooptation of Hospice

The U.S. hospice movement has proved enormously successful, growing from one hospice in 1974 to 3,300 in 2003 and serving almost 1 million clients annually (National Hospice and Palliative Care Organization, 2001). As the movement has spread, however, it has undergone substantial **cooptation**, exchanging much of its initial philosophy and goals for social acceptance and financial support (Finn Paradis and Cummings, 1986; Mor, 1987: 17).

The history of hospice resembles the history of many other reform movements and organizations. As various sociologists have observed, successful social movements over time often come to resemble the very institutions they sought to reform (DiMaggio and Powell, 1983; McCarthy and Zald, 1973). These changes evolve gradually and naturally. For a movement to survive, it must mobilize people and develop sources of funding. To do so, reformers typically must develop hierarchies and rules, abandon their grassroots and voluntaristic approach, and hire professional staff. Battered women's shelters, for example, initially established by feminists as a radical means of protecting women from violent men, soon came to rely primarily on social workers whose goal is restoring the family unit (Schechter, 1982).

The cooptation of hospice similarly derives from natural developments in that field, especially the need to develop a stable economic base. Initially, many hospice organizers, reflecting the countercultural values of

the late 1960s and early 1970s, expressed little concern for financial stability (Abel, 1986: 75). Very quickly, though, and despite qualms among some hospice organizers, hospices began to seek federal funds to support hospice development, as well as **third-party reimbursement** (that is, the ability to bill insurers for services rendered).

To gain support, organizers worked with the federal government and with the American Hospital Association to develop standards for hospice care and accreditation. The resulting standards legitimated hospice care and paved the way for Medicare and, later, Medicaid and private insurance reimbursement. Not surprisingly, they also made hospices more like hospitals.

Medicare funding and the associated federal regulations also have changed hospices and threatened the original hospice philosophy (Finn Paradis and Cummings, 1986). For example, Medicare will not reimburse hospices for costs above its set maximum number of dollars and number of days of care per patient. In addition, it will reimburse hospices for the cost of inpatient care only to the extent that inpatient care comprises no more than 20 percent of all care given. These regulations encourage hospices to accept patients who have sufficient family support to stay at home rather than in the hospice, who are near death, and whose time of death can be predicted with reasonable accuracy. In addition, to obtain reimbursement, hospices must provide services that meet specified standards and must document these services. These requirements have made it difficult for hospices to maintain their commitment to individualized care and to patient control and participation.

Medicare and private insurers also have placed limitations on who can provide care, requiring hospices to reduce their reliance on volunteers, social workers, ministers, and the like, and instead to hire professionally trained health care workers and administrators. These latter individuals often bring with them traditional ideas about health care, about the health care team, and about dying itself. Former hospital nurses, for example, might resist allowing patients to refuse intravenous feeding because that seems an unacceptable admission that health care has failed and might resist allowing patients to choose when to receive medications because the nurses prefer the ease of a hospital-like schedule (Abel, 1986: 77).

Internal pressures have forced other changes in hospice care. The original hospices were freestanding units, unaffiliated with other health care institutions. This model has proved both financially and administratively unfeasible. Freestanding hospices lacked ready access to the support services available at hospitals and other health care institutions. In addition, their independent status hampered efforts to get funding and to get referrals of patients from hospitals. As a result, although two-thirds of hospices remain nonprofit, most no longer are independent, community based, or largely volunteer run. (Box 10.2, however, describes one inspiring exception.) Hospitals or home health care agencies own most of the rest. Yet despite these changes, studies find that hospice clients and their families feel more

Box 10.2 ***Making a Difference: The Human Service Alliance***
by W. Bradford Swift with Kimberly Ridley

The Human Service Alliance (HSA) is an experiment both in delivering free health and social services and in voluntarism as a way of life. In addition to its Care for the Terminally Ill (CTI) facility, the organization runs . . . a weekend respite program for families with disabled children . . . and a health and wellness program for people with chronic illnesses. Even the administrative jobs here, from accounting to filing, are performed by HSA's twenty-four volunteer board members.

In 1996, HSA volunteers provided 70,000 hours of service work, the equivalent of thirty-five people working full time. They delivered an estimated \$926,800 worth of services . . . on a total operating budget of just \$80,000, which comes from individual contributions and a few grants from area corporations. In the 11 years since the organization's inception, its methodologies have drawn the attention of administrators from nursing homes and schools of medicine and public health. One visiting physician, a cancer specialist, remarked after perusing the caregiving charts and detailed notes on each patient, "In the hospital, we cannot come close to offering this kind of attention, and having the rapport that HSA's caregivers do."

Forty-seven guests spent their final days in the CTI wing, twenty-four families utilized the

services of the Respite Care Program, and twenty individuals with chronic health problems were served by the Health and Wellness Project in 1996. . . .

Human Service Alliance began in 1986 when a handful of people in remote Boomer, North Carolina, started taking care of one terminally ill neighbor at a time in makeshift quarters in a refurbished trailer. . . . By 1988, a core group had evolved, incorporated HSA, and moved the organization to the outskirts of Winston-Salem. They committed to operating debt-free by recruiting volunteers and raising donations before spending money. Within a few years, they had raised \$400,000 to build HSA's facility for the terminally ill, which opened in 1991. . . .

Perhaps among all of HSA's programs, the Care for the Terminally Ill unit is where some of the most intensive services are provided. The unit, which accommodates up to six terminally ill "guests" in private and comfortable rooms, helps fill an important gap by caring for dying individuals who don't require the medical services of a traditional hospice, but whose families are unable to care for them at home. . . .

All guests accepted onto the CTI unit are selected by a committee of board members based upon the organization's ability to care for their specific needs, the guest's willingness to live out his or her final days at HSA, and the

satisfied with their care than do those who receive care from conventional sources (Mor, 1987: 150-156).

Use of Hospice

About one of every four persons who die in the United States uses hospice services, with most of these over age 65 (National Hospice and Palliative Care Organization, 2005). Whites, who make up about 75 percent of the general

family members' willingness to be a part of the process of their loved one's death. . . .

Family members are expected to visit regularly and are encouraged to volunteer some of their time serving at HSA, not because more volunteers are needed, but because it's been found that volunteering is often therapeutic for the family. Using volunteer activity in a therapeutic manner has also worked well in HSA's Health and Wellness program for clients with chronic illness. Todd Thornburg, a board member who started the program in 1988, says volunteering seems to be some of the best medicine the organization has to offer. He describes one young woman who entered the Health and Wellness program a few years ago with the complaint that her physician had ruined her knee and her life [through botched surgery]. Volunteering allowed her to redirect her focus, Thornburg says, adding that when she completed the program approximately a year later, she had a new life before her, even though she still had a knee that didn't work properly. . . .

Inspired by their experiences at HSA, a few volunteers have begun developing their own projects back home. Two free, volunteer-run hospices have opened in Jamesville and Fredericksburg, Virginia, [while] in Blue Hill, Maine, writer and former HSA volunteer

Maggie Davis launched Neighborcare, a program in which local volunteers clean, cook, run errands, and provide other help for the sick, elderly, injured, or overwhelmed in their community. "We see ourselves as filling in the gaps where people don't have what they need," Davis says. At first, Davis had in mind a center for the terminally ill, but when she met with representatives from area hospitals and social service organizations, they described more basic needs like rides to and from appointments, companionship, and simple caring. Davis put out the word, and a year and a half later, approximately seventy volunteers are ready to assist their neighbors in a handful of surrounding towns. . . .

The board members and founders of HSA hope to inspire other efforts around the nation and in other countries. But how does the average person find time in a busy life for this kind of work? "Serve in a group," suggests board member Danziger. "If eight people get together and want to serve a respite child, each could do two hours of work a week to give their parents a substantial break. The important thing is to start small and start now." . . .

Source: "Where Care Is Free." *Hope Magazine*, November–December 1997.

population, make up 81 percent of hospice users. Median length of services for hospice clients is only 22 days.

Because the early British hospices focused on cancer patients, American hospital staff from the start associated hospice care with cancer and therefore more often referred such patients to hospices. Hospices themselves are more likely to accept patients with cancer because doctors can predict their life expectancy fairly accurately, and thus hospices can assume that any

cancer patient they accept will die within the six-month Medicare guidelines. In 2003, 49 percent of hospice clients had cancer (National Hospice and Palliative Care Organization, 2005). Conversely, the greatest unmet needs are found among dying patients who do not have cancer.

Costs and Financing

Hospices depend heavily on Medicare funding. Seventy-nine percent of hospice users rely on Medicare to pay the costs. Another 13 percent rely on private insurance, 5 percent on Medicaid, and the remainder on a variety of sources (National Hospice and Palliative Care Organization, 2001).

Whether hospice care saves money compared with other options remains unclear (Mor, 1987: 177–212). Direct costs appear somewhat lower for hospital-based hospices than for traditional hospital care, but indirect costs are substantial (Kidder, 1988a, 1988b; National Hospice and Palliative Care Organization, 2001). Currently, half of hospice users die in their homes, and only 7 percent die in hospices (National Hospice and Palliative Care Organization, 2005). In these circumstances, family members provide most care. They often must take time off from work or drop out of the labor market altogether. Consequently, hospice care might not reduce the costs of caring as much as it shifts the costs from hospitals and insurers to families.

Home Care

As the discussion of hospices has suggested, most individuals who experience chronic or acute health problems—whether children, working-age adults, or elderly, and whether the problems are physical or mental—receive their care at home (Abel and Nelson, 1990). This is even truer now than in the recent past due to technical, demographic, and policy changes. Because of technological advances, babies born prematurely or with birth defects and persons who suffer severe trauma are increasingly likely to survive, although often with severe disabilities that require lifelong assistance. Much of this care is now given by family members in the home.

Similarly, the rise in the numbers of frail elderly, many of whom suffer both multiple physical problems and cognitive impairments, has increased the number receiving care at home. At the same time, technological advances also have made it possible for families to provide at home treatments previously available only in hospitals, ranging from chemotherapy to respiratory ventilation to kidney dialysis. In addition, the movement begun in the 1960s (and described in Chapters 6 and 7) to deinstitutionalize disabled and mentally ill persons, combined with the lack of community supports for such individuals once deinstitutionalized, have shifted much of the burden of care from state institutions to the home. Finally, as described earlier, policy changes now encourage hospitals to discharge patients to their homes “sicker and quicker,”

in essence replacing paid hospital workers with unpaid family caregivers (Glazer, 1993).

Because of the limited public or private insurance funding for home care, most who need long-term supportive care receive services only from family members and, less often, friends. The economic value of home caregiving has been estimated at \$257 billion per year, much greater than the amount spent per year on paid home care or nursing-home care (National Alliance for Caregiving and AARP, 2004). Existing data suggest that home care has little impact on the costs of care or the mental or physical functioning of ill or disabled individuals but can produce small, short-term improvements in their life satisfaction (Arno, Bonuck, and Padgug, 1995; Weissert, 1991).

The Nature of Family Caregiving

A survey conducted for the nonprofit organizations National Alliance for Caregiving and AARP (2004) found that 21 percent of U.S. households include someone who is providing care for a person over age 18; it also found that the majority of these caregivers (61 percent) are women. Ethnic minorities and poorer persons also are more likely to become caregivers, probably because these groups experience higher rates of illness and disability and have less access to formal services.

Those who care for the health needs of family members typically do so out of love and often reap substantial psychological rewards. Yet, caregiving by family members should not be romanticized, nor should the financial, physical, social, or psychological costs of caregiving be underestimated (Abel, 1990; Abel and Nelson, 1990; Arras and Dubler, 1995; National Alliance for Caregiving and AARP, 2004; Reinhard and Horwitz, 1996; Tessler and Gamache, 1994).

The financial costs of caregiving are substantial. The demands of caregiving force many to shift to part-time work or even abandon paid employment. In addition, caregivers must purchase, often out of pocket, both expensive drugs and technologies and many everyday items such as diapers and bandages. In addition, caregivers typically are responsible for purchasing a variety of services and therapies from a range of companies and health care workers.

The physical costs also can be high. Caregiving often includes exhausting tasks such as lifting physically disabled or mentally incompetent individuals, some of whom either cannot help or resist being moved. The time burdens of caregiving also can become physically draining. The typical caregiver spends more than 20 hours per week on caregiving and has done so for 4.3 years; 17 percent work 40 hours or more. These hours quickly lead to exhaustion, especially for the 59 percent of caregivers who hold paid jobs, the 37 percent who have children at home, and the 31 percent who care for more than one person (National Alliance for Caregiving and AARP, 2004).

Not surprisingly, those who report giving high levels of care (helping with numerous activities of daily living for long hours) also report substantial health problems and physical strain.

Taken together, the financial and physical burdens of caregiving often leave individuals with little time, energy, or money for social relationships. Caregivers often report feeling almost totally isolated from the world outside the household (Abel, 1990; Abel and Nelson, 1990). Family relationships, too, can suffer. For example, a mother who spends hours each day caring for an ill child might feel guilty that she cannot spend more time with her other children, and those children might resent the attention given to their ill sibling. Problems are particularly acute when the person receiving care is mentally ill and throws family routines into chaos, embarrasses other family members, or physically threatens others' safety (Reinhard and Horwitz, 1996; Tessler and Gamache, 1994).

Family life also can suffer disproportionately when caregiving requires the use of high technology within the home. John D. Arras and Nancy Neveloff Dubler suggest that this

invasion of the home by high-tech medical procedures, mechanisms, and supporting personnel exerts a cost in terms of important values associated with the notion of home. How can someone be truly "at home," truly at ease, for example, when his or her living room has been transformed into a miniature intensive care unit? . . . Rooms occupied by the paraphernalia of high-tech medicine may cease to be what they once were in the minds of their occupants; familiar and comforting family rituals, such as holiday meals, may lose their charm when centered around a mammoth Flexicare bed; and much of the privacy and intimacy of ordinary family life may be sacrificed to the institutional culture that trails in the wake of high-tech medicine. (1995: 3)

Finally, caregiving brings with it numerous psychological costs. Caregivers can easily become depressed when their efforts cannot stop or even slow the disease process. This is especially true when caregivers must routinely inflict painful treatments on their charges or when the burdens of caregiving are unceasing, as when a parent must suction the lungs of a child with cystic fibrosis hour after hour, day after day, to keep the child from dying. Moreover, as this example suggests, caregivers also often bear the enormous psychological burden of being directly responsible for another person's life. In fact, family caregivers are now expected to manage in the home—often with little training or technical support—technology considered too complex for licensed practical nurses to manage in hospitals. Finally, caregivers of persons younger than themselves face anxieties about what will happen to their charges if the caregivers die first.

Summing up the burdens of caregiving, a woman whose husband has Parkinson's disease says:

I need some help. I am burned out. I am locked in this house. I am used to going out to work and had to retire. I didn't plan to retire so soon. We had planned our

retirement. We never did anything before because we didn't have the same vacation time. So you do all this and then bingo! . . . Two weeks ago I had a terrible pain in my ribs. But I can't run to the doctor for every little thing. How can I leave the house? I worry, what is going to happen to him, if I have to go to the hospital. . . . Medicare pays for only part of the things we need and doesn't pay for medications. That bottle of medication cost \$130. . . . Sometimes he has to go to the bathroom just when I've finished eating. It is hard to get up at that instant to do it. You feel like everything [you just ate] is going to come up. You have all these things to contend with. People don't realize that unless they are in those situations themselves. . . . You have to really see it for yourself, be in it, to know what it is like. (Corbin and Strauss, 1988: 297)

Easing the Burdens of Caregiving

The problems faced by family caregivers have led to the development of new organizations, new organizational structures, and a new occupation to ease the burdens of caregiving. Two major organizations, the National Alliance for the Mentally Ill and the National Alliance for Caregiving, are now devoted to family caregiving. Both organizations work to increase assistance to family caregivers and improve access to community-based care, and the National Alliance for the Mentally Ill additionally fights to decrease the stigma of severe mental illness.

Both **respite care** (R. Montgomery, 1992) and **family leave programs** also were developed to ease the burdens of caregivers. Respite care refers to any system designed to give caregivers a break from their otherwise unrelenting responsibilities, including paid aides who provide care in the home for a few hours, day-care centers for elderly and disabled adults, and nursing homes that accept clients for brief stays. Unfortunately, only California and Pennsylvania offer formal programs for respite care. In all other states, respite care is expensive and difficult to find; only 5 percent of those included in the National Alliance for Caregiving and AARP (2004) survey had ever used respite care. Minimal data are available on the quality of these services (Kitchener and Harrington, 2004).

The concept of family leave received considerable public attention with the 1993 passage of the federal Family and Medical Leave Act. This act gives employees the right to as many as 12 weeks of unpaid leave from work yearly to care for family members. Although the law has benefited some family caregivers, its impact has been muted because only more-affluent Americans can afford to take unpaid leaves and because the law does not apply to part-time workers, temporary workers, or employees of small firms. In addition, the law is problematic because it reinforces the idea that caring for ill and disabled persons is the responsibility of the family—which, in practice, usually means women relatives—rather than the responsibility of society as a whole (Abel, 2000).

Finally, those who provide care to relatives or friends may turn for assistance to paid caregivers. Each day about 1.4 million Americans receive paid home care, most commonly in the form of help with bathing, dressing, and light housework (National Center for Health Statistics, 2005). Most paid home care is provided by **home health aides**, who typically have no formal training, or **registered nurses**, who have received at least two years of nursing training and passed national licensure requirements. Aides are overwhelmingly minorities and women, and they are highly likely to be immigrants. Few receive any job benefits, and most receive only minimum wage. Because the growth in paid home health care is so new, little more is known regarding these workers or their work.

Health Care Technologies

Since the start of medicine—and indeed, before—doctors and other healers have used technologies in their work. Two hundred years ago, doctors used knives to cut veins and “bleed” patients of their illness, and they used strips of cloth to bandage the wounds afterward. One hundred years ago, doctors used mercury compounds and electricity in attempting to cure patients of masturbation or syphilis. In modern medicine, health care technology includes everything from Band-Aids to computerized patient record systems to heart-lung machines.

The Nature of Technology

Technology refers to any human-made object used to perform a task. In addition, the term is often used to describe processes that involve such objects. For example, the term *technology* can refer both to the overall process of kidney dialysis and to the equipment used in that process.

Although we often talk about technology as if it is inherently either good or bad—“technology has made our lives easier,” or “technology has depersonalized medical care”—the reality is more complex (Timmermans and Berg 2003b; Heath, Luff, and Svensson, 2003). It is true that the nature of a technology determines the *range* of ways it might be used, but whether it is harmful, helpful, or both depends on *who* uses it in *which* ways. Electricity is helpful when used by doctors to stimulate muscle healing and harmful when used by doctors who are poorly educated or are employed as torturers in dictatorships. Fetal monitors can depersonalize childbirth when nurses stare at the screens rather than pay attention to the pregnant woman. But ultrasound imaging of fetuses can *personalize* pregnancy for fathers, who literally visualize their future children as real for the first time. In addition, such technologies can create a setting in which fathers, mothers, and health care workers can discuss the emotional aspects of pregnancy and child-rearing.

Similarly, we often talk about technology as if it is either a blank slate, lacking any inherent nature, or a force outside of human control. Again, the

reality is more complex. For example, there has been considerable pressure lately for doctors and hospitals to reduce medical errors by adopting computerized medical databases to standardize the collection of patient data (Timmermans and Berg, 2003a). The purpose of these databases is to eliminate human error and variability in this process. For this reason, computerized databases may prompt doctors to ask their patients a specific set of questions, in a specific sequence, with a specific set of prompts if the answers seem insufficient or inappropriate. In this way, the database program presses doctors to standardize their practices, and encourages them to focus on certain areas to the exclusion of others and to organize the data they obtain in specific ways. At the same time, doctors quickly learn how to obtain at least partial control over the database through the way they ask their questions and the answers they record to the database's questions. Similarly, although patients are pressed by the nature of the database to respond within a narrow framework, they often sidestep the questions they are asked and instead address a different set of issues.

When we study technologies sociologically, therefore, it is as important to study the cultural system that surrounds that technology and determines how it will be used, by whom, and for what purposes, as it is to study the nature of the technology itself. Yet while we explore how society and social actors shape the use of technology, we also need to explore how *technology* shapes society and social actors.

In this section we will look at how technologies develop and become adopted. We will also consider how different groups within the health care world interact with technology—and with each other.

The Social Construction of Technology

In the same way that we have talked about the social construction of illness, we can talk about the **social construction** of technology: the process through which groups decide which potential technologies should be pursued and which should be adopted. This concept in turn leads to the question of who promotes the social construction of any given technology, and who benefits from this?

As is true for the social construction of illness, the social construction of technology is a political process, reflecting the needs, desires, and relative power of various social groups. These groups can include manufacturing corporations, doctors, the government, and consumers. As a result, harmful technologies are sometimes developed and adopted, and needed technologies sometimes are not.

One fascinating example of the social construction of technology is the history of cardiopulmonary resuscitation (CPR). The purpose of CPR is to restore life to those whose hearts and lungs have stopped working. In earlier times, the very notion of such resuscitation would not have made any sense to doctors or the public. Death was considered to be in God's hands, and

dead was dead. But since the rise of modern medicine, doctors have struggled to find ways to restore life to those who suddenly die.

At the same time, doctors have grown increasingly able to understand the slow trajectory of dying associated with cancer. And with the rise of the hospice movement (described earlier in this chapter), both doctors and the public have come to hold as an ideal the “good death,” in which an individual comes to terms with his or her dying, has the time to make peace with family and friends, and receives appropriate terminal care to minimize physical and emotional suffering.

None of this, however, applies to the sudden—and common—deaths caused by stroke or heart disease. In his award-winning book *Sudden Death and the Myth of CPR*, sociologist Stefan Timmermans (1999) argues that CPR and associated resuscitation techniques have become part of American medical culture because they appear to offer a “good death” in these circumstances. Innumerable television dramas portray heroic doctors who save apparently dead patients through CPR, and millions of dollars have been spent teaching the general public to perform CPR and outfitting community emergency response teams and hospital emergency rooms with resuscitation equipment. Yet CPR is almost never effective except when otherwise healthy individuals drown or are struck by lightning. The typical person who receives CPR has *at best* a 1 to 3 percent chance—and probably much less—of surviving, at an estimated cost of \$500,000 per survivor. Moreover, “survival” may be brief, and it may be accompanied by severe neurological damage. As a result, the emergency room doctors and emergency medical technicians Timmermans observed and interviewed overwhelmingly regarded resuscitation as futile, and so they joked, complained, or simply went through the motions when they had to use it.

Why, then, has CPR become so widely adopted? Timmermans argues that the widespread use of CPR reflects modern Americans’ discomfort with death. The real benefit of CPR, according to Timmermans, is that it “takes some of the suddenness of sudden death away” (1999: 110). CPR allows families and friends to believe they have done everything possible by getting their loved ones to treatment as fast as possible. It also gives families and friends time to gather and to recognize that death may be imminent, and it gives medical personnel a sense of technical accomplishment as they fight to keep their patients’ bodily organs functioning as long as possible. For these reasons, and despite all its emotional and financial costs, CPR has become a valued and expected ritual in American culture.

At the same time, adoption of CPR illustrates the economics and politics, as well as the cultural forces, that underlie the social construction of technology. CPR would not have been so widely adopted if corporations had not had a vested economic interest in promoting it. Nor is it likely that CPR would have become the norm if corporations had been required to demonstrate its effectiveness before selling it. In fact, however, there are almost no legal requirements for corporations to demonstrate the safety or

effectiveness of technical devices. As a result, manufacturers of medical technologies (unlike drug manufacturers) have no reason to fund such research. Doctors thus must depend on promotional materials from manufacturers and on their own clinical experiences in deciding whether to use a technology, and patients must rely on doctors' judgments.

Conclusion

In this chapter, we examined three difficulties inherent in the ways we provide care to those who are physically or mentally ill or disabled. First, we looked at some of the inherent contradictions of trying both to provide care and to make a profit. Health care workers, from medical students to home health aides, laboring long hours under often brutal conditions to keep their employers' costs low, cannot provide the quality of care they might like. Even institutions such as hospices, for whom profit making is not a primary motive, must contend with the demands of a wider system that emphasizes cutting costs and generating profits. Meanwhile, other institutions, such as nursing homes, board and care homes, and home health agencies, have emerged specifically to make money, relegating caregiving to a secondary priority.

Second, we considered the difficulty of providing individualized care in institutional environments. Almost by definition, large institutions must provide care en masse, ignoring individual preferences and desires. Patients must follow rules, schedules, and regimens established for the sake of efficiency, regardless of the impact on patients' quality of life. This tendency to ignore the individual is further reinforced because it is far cheaper to provide regimented rather than individualized care.

Third, we explored some of the inherent difficulties of treating health care as an individual or family responsibility rather than a social responsibility. As we have seen, the burdens of caregiving can be enormous. Yet the United States offers little support to those who take on this responsibility. In contrast, other industrialized nations provide far more assistance; both Sweden and Finland, for example, allow parents of sick children to leave work for several months while still receiving most of their salaries, and they provide free or inexpensive assistance with domestic chores to elderly persons who might otherwise have to turn to family members for assistance (Swedish Institute, 1997, 1999; Zimmerman, 1993).

In sum, the data presented in this chapter regarding the virtual social abandonment of ill and disabled individuals and of their caregivers suggests the low priority this society places on caring for those who are weak or ill, especially if they also are poor. Technology is not a panacea for these problems. Nor, for that matter, is it inherently dehumanizing or otherwise problematic. Rather, technology is a tool, adopted for a combination of cultural, medical, emotional, and financial reasons, that can be used for good or ill. Only when our underlying social values and commitments change can we expect the lives of ill persons, disabled persons, or their caregivers to improve significantly.

Suggested Readings

Annas, George J. 2004. *The Rights of Patients: The Authoritative ACLU Guide to Patients' Rights*. New York: New York University Press. Written by one of America's foremost experts on health law.

Gass, Thomas E. 2004. *Nobody's Home: Candid Reflections of a Nursing Home Aide*. Ithaca, NY: ILR Press. A riveting account of life in nursing homes, describing the experiences of both residents and nursing assistants.

Timmermans, Stefan. 1999. *Sudden Death and the Myth of CPR*. Philadelphia: Temple University Press. How CPR became part of American culture and medical care—even though it almost never saves lives.

Getting Involved

National Alliance for Caregiving. 4720 Montgomery Lane, Suite 642, Bethesda, MD 20814. (301) 718-8444. www.caregiving.org. Provides information and support to family caregivers of the elderly and to health care providers working in the field. Also collects and disseminates information about the value of family caregiving and the burdens borne by caregivers.

National Citizens' Coalition for Nursing Home Reform. 1424 16th Street, N.W., Suite 202, Washington, DC 20036-2211. (202) 332-2275. www.nccnhr.org. Citizens' action group seeking reform of nursing homes and board and care homes.

Review Questions

In what ways were nineteenth-century hospitals total institutions?

What led to the development of voluntary hospitals? veterans hospitals? government hospitals? the modern hospital as we know it?

What was the original philosophy of hospices, and why and in what ways has it changed?

What is patient dumping, and why does it occur?

Who uses nursing homes?

What is the difference between nursing homes, board and care homes, and assisted living facilities?

How does the process of commodification affect nursing assistants and nursing-home residents? Why has home care grown? What are the difficulties faced by family caregivers?

What is technology? What do sociologists mean when they say that technology is inherently neither good nor bad, and neither a blank slate nor a force outside of human control?

What is the social construction of technology? What does it mean to say that this is a political process?

Why was CPR so widely adopted even though it was so ineffective?

How can society shape technology? How can technology shape society?

Internet Exercises

1. Do a search at google.com for alt.support.alzheimers, a discussion group for persons who care for individuals who have Alzheimer's disease. Once you get to the discussion group's website, read a few "threads"—queries and the answers posted to them—to identify some of the issues faced by these caregivers. Do discussion groups seem to be effective means of helping family caregivers?
2. Using the Internet, find three websites advertising nursing homes or assisted living facilities. What information would you want if you needed to place a relative in such a facility? What information do these websites leave out? How does each website encourage you to believe that its facility would be the best one for your relative?

