

Home Care

Caring for the Sick at Home

Patients with disabling illnesses have always required a complex assortment of private, voluntary, and public organizations to supplement family caregiving. The needs of these patients disrupt daily activities; inevitably have financial consequences; and require skilled caregiving, ingenuity, and resourcefulness. Despite these challenges, the idea of caring for the sick in their homes retains a special appeal as practical, necessary, family-oriented, and perhaps cost-effective. After two centuries of experimentation, however, we in the United States have failed to create a comprehensive or coordinated approach to the provision of home care. It is the needs of the growing number of chronically ill patients who neither get well nor die that confounds our ability to develop a successful system of community-based care. To date, no agreement exists concerning the balance between the public and private resources to be allocated through state funding, private insurance, and family contributions for patients requiring care at home. For a society ambivalent about whether caring for the sick at home is a family responsibility or one shared by the larger society, investing in the long-term needs of the chronically ill remains an unresolved public policy issue.

Origins of Organized Home Care

In the early nineteenth century, care of the sick, birthing, and dying were all part of domestic life, while hospitals were places of last resort for

those without families or caring neighbors. Families of sufficient financial means hired doctors, nurses, or midwives to deliver care in the patient's home when assistance was required. By the end of the nineteenth century, benevolent ladies across the United States were creating organizations to send trained nurses into the homes of the sick poor to provide care and prevent the spread of their dangerous contagious diseases. But from the beginning, these organizations encountered what they described as the vexed question of the chronic patients: which of the chronically ill most deserved care, and how long could they be cared for before they threatened the organization's financial viability? Clearly, limiting care to the acutely ill who through good nursing could be quickly returned to the care of their families seemed the most cost effective investment.

Insurance Coverage for Home Care

Most of these "visiting nurse associations," as they were called, financed their work through modest philanthropic donations. But their financial circumstances were dramatically improved when, in 1909, the Metropolitan Life Insurance Company (MLI) established an insurance scheme for home nursing care for their policyholders. The principal objective of MLI's contracts with visiting nurse associations was the restoration to health and work of policyholders who were ill. The economic incentives were obvious. By increasing policyholders' life spans, fewer death claims would be collected; premiums could be lowered; and this, in turn, would attract more policyholders. By 1916, this service was available to the majority of MLI policyholders across the country. That year 221,566 policyholders received over one million nursing visits.

As the nursing service grew and MLI accumulated more data, it became obvious that “scientific case management” would be essential if insurance coverage of home care were to be cost-effective. This strategy’s focus was standardization of nursing practices and elimination of what MLI saw as “useless cases.” The financial reality was that when the desired outcome was life extension, it did not pay to care for the chronically ill.

But by the 1920s, there began a dramatic upward trend in mortality from chronic disease as the proportion of elderly in the population rose. Policyholders were living longer, dangerous communicable diseases were a thing of the past, and hospitals were increasingly assuming responsibility for the care of acutely ill patients. Increasingly, the patients cared for at home were the chronically ill. The key question was whether the insurance company could establish a payment system that was stringent enough to avoid paying for long term personal care (such as the activities of daily living), elastic enough to care for patients with the potential to recover, and humane enough to cover the care of patients requiring skilled care to minimize suffering. First studied in 1928, this remained an unresolved policy dilemma in the United States. The results showed that from an insurance perspective the answer was "yes." But the question remained, who would provide day-to-day care for the growing numbers of patients who failed to get well or die?

There were increasingly institutional alternatives to community-based care for the chronically ill: hospitals, almshouses, and private nursing homes. In 1935, the creation of Old Age Assistance (Social Security) rebalanced the locus of care for the chronically ill. Over the years, the result was an incremental expansion of private nursing homes for the chronically

ill. For families unable to provide care at home these institutions offered an alternative.

By the 1930s and 1940s, it was argued that the demands of the chronically ill were compromising the capacity of hospitals and that perhaps home care could provide a preferred and less expensive alternative to hospital care. How to pay for this care remained a dilemma. What followed were decades of study, experimentation, and recurring interest in home care. Repeatedly, it was concluded that only in cases of serious illness where coverage was limited to brief acute episodes was home care a reasonable benefit to include in insurance programs. Caring for the chronically ill at home remained a private/family responsibility. As advocates for the chronically ill argued, only a reconceptualization of service delivery and financing would produce the comprehensive, centrally coordinated approach required by these patients.

Federal Policy for Home Care

In the end home care was included in the Medicare, Medicaid, and the Older Americans Act initiated in the 1960s. It was home care's presumed ability to empty hospital beds that resulted in its inclusion in the Medicare program. The argument that home care would save money always assumed the availability of unpaid family caregivers who would supplement professional care. Care covered by Medicare was limited to medically necessary, intermittent skilled care for the homebound acutely ill following hospitalization. It was not designed to reduce the growing burden of chronic disabling illness.

Monies for most of these programs were collected by the federal government, and intermediaries redistributed the funds to individuals to subsidize their purchase of home care services in the private market. The result was a vast array of categorically linked and narrowly defined community-based services for the elderly. This federally financed and regulated pluralism effectively prohibited the development of any coordinated system of care. The outcome for many patients was a confusing assortment of programs with different payment requirements, eligibility criteria, and systems of reimbursement, as well as coverage limitations that created gaps in the services people received when they had to stay at home because of illness.

Integration of acute and community-based services became the buzz phrase in health-care reform by the 1990s. Social health maintenance organizations, Programs for All-inclusive Care for the Elderly, a variety of state waiver plans, and even health management organizations (HMOs) attempted to integrate and coordinate care across settings. Within these new approaches, home care was valued as an important component of the continuum of care rather than a cost-saving alternative to institutional care. Much has been learned through these experiments with financing and service delivery, but no universally acceptable “American way” of delivering comprehensive and coordinated community-based care has been identified. Most of these new paradigms of care conflict with the customary practice of medicine, limit patients’ individual freedom and choice of provider, and confront our uncertainty about providing social welfare services and support to family caregivers.

Over the years, legislative, judicial, and regulatory changes resulted in exponential expansion of home-care benefits. By the 1990s, Medicare, a

program designed to meet the needs of short-term acute illness was also providing long-term care to the chronically ill. Ambiguity over interpretation of benefits had created the opportunity for providers of home care to recast the Medicare regulations to better meet a broader set of patients needs. While presumed reasonable, necessary, and medically appropriate, home care's expansion was deemed unsustainable. On October 1, 1997, the Balanced Budget Act of 1997 radically transformed the Medicare home-care benefit enacted in 1965. The outcome was swift: over 3,000 agencies closed, the number of visits per patient decreased, and public funding for home care was dramatically reduced. More recently, the introduction of a new prospective payment system has meant yet another reinvention of care at home. As with MLI's scientific case management, the goal was an intensive and targeted approach to home care. Once again financial incentives dictated fewer visits, a focus on skilled versus personal care, briefer episodes of care, and a rapid transfer of ongoing care to the family.

The Burden of Family Caregiving

Today the vast majority of those caring for the growing number of elderly and for children and adults with developmental or physical disabilities are family or friends. A 2004 study found that one in five (22.9 million) U.S. households were involved in caring for a person older than eighteen. Sixty-one percent of these caregivers were women who provided more than twenty hours of care each week to their mothers. The National Association for Home Care's recent studies estimate the economic value of this care as \$257 billion. This investment far exceeds government spending for either home or nursing home care. Family caregiving is complex, costly, and exhausting, and family caregivers may continue for years without

assistance or training from professionals. The burden of family caregiving remains a multifaceted and enormous policy issue.

Conclusion

The history of caring for the sick at home explains much about our current challenges and their possible resolution but only if we are willing to confront an enduring set of questions:

- Is caring for the sick at home a private family obligation or a responsibility shared with a caring society?
- Should professional home care be provided only under the most restrictive of circumstances or whenever it can help?
- Should we simply continue to muddle on depending primarily on informal caregivers—mostly women—to house, feed, and meet the medical needs of the sick at home?

References

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