

Long-term Care and AIDS: Perspectives from Experience with the Elderly

A.E. BENJAMIN

*University of California,
San Francisco*

IN THE VIEW OF MANY OBSERVERS, AIDS REPRESENTS a new set of problems for the health care delivery system, one for which a new set of solutions must be developed. Those who take a longer view of the history of public health, however, would challenge this perspective. They cite the long experience of governments in addressing the threats of infectious diseases generally, and sexually transmitted diseases particularly (Lee and Benjamin 1984), although the extent to which the American health polity has been prepared by this experience to respond effectively to the disease has been questioned (Fox 1986). Critics have noted that while considerable expertise related to health promotion and disease prevention has been developed in recent decades, what is lacking in response to AIDS is not expertise but political will and fiscal resources (Fox 1986; Lee 1986; Lee and Arno 1986).

This article will argue that with respect to the organization, financing, and delivery of health care services to persons with AIDS, there is another body of knowledge and experience on which we may draw in what may seem an unlikely place, namely long-term care for the elderly. For the past two decades and particularly since the late 1970s, considerable policy innovation and research have been directed at issues associated with service responses to chronic illness among the elderly. Despite both real and apparent differences between the young adult

population afflicted with AIDS and the frail elderly with chronic illness, there are some important similarities between the problems facing these two populations and the broad solutions available to them. This article will argue that many of the most significant service responses by government and the private sector to the AIDS crisis have been adapted from service experience with the elderly. I will argue also that while learning with respect to innovative service planning has been rapid in the expanding field of AIDS care, much less attention has been paid to a large body of research on care for the elderly that raises important and complex questions about the goals and impact of various approaches to the care of the chronically ill.

Why AIDS and Aging Pose Similar Problems

Recent research suggests that an estimated 12 to 18 percent of persons over the age of 65 can be considered frail and dependent (Branch and Jette 1981; Weissert 1985a; Branch et al. 1984; Manton and Soldo 1985), and for most of this population the source of their debilitation is chronic illness that may involve acute episodes and for some may be considered terminal. Regardless of its specific etiology and disease course, AIDS shares certain essential characteristics with many conditions affecting the frail elderly, i.e., it is chronic, debilitating, and terminal. Like chronic care for the elderly, AIDS care represents a strain on a health care system designed to provide episodic and medically oriented services. Like the frail elderly, most persons with AIDS spend a majority of their time outside the hospital and physician's office and thus must rely upon supportive and personal care services provided at home or in other residential settings in order to live in the community. For a majority of persons in need, whatever their age or condition, such services remain in short supply, unless the person in need is both resourceful and prosperous enough to locate and purchase care privately. As with the elderly, persons with AIDS primarily depend upon an informal network of relatives and friends to provide most needed supportive and personal care (e.g., shopping, eating, bathing, etc.), and the burden of care on informal care givers can be considerable. Like a growing number of the elderly (Bishop 1986; Commonwealth Fund Commission on Elderly People Living Alone 1987), however, many persons with AIDS either live alone or are reliant for care upon

persons who themselves are vulnerable to illness and dependency (e.g., elderly parents or at-risk spouses or lovers).

If there are some important similarities in the kinds of problems created for policy makers by the AIDS epidemic and by chronic illness among the elderly, there are also significant parallels between the kinds of solutions proposed to address the care needs of these populations. Although it is likely to grow rapidly, published literature on AIDS policy and service delivery remains relatively scant, considerably more so than that related to the epidemiology of the disease. Like much of the significant debate in recent decades regarding health care policy for the elderly, current policy research on AIDS is dominated by the study of the costs of care, and what little analysis of alternative models of service organization and delivery that has been done is within the context of their impact on the costs of caring for persons with AIDS (Sisk 1987; Arno 1986).

The central argument of this article is that public and private planning for AIDS have emphasized potential service solutions to the acute and chronic care needs of persons with AIDS without acknowledging the various complex issues associated with their development and implementation. This tendency to embrace policy solutions uncritically is itself not confined to planning for AIDS but has been the subject of much discussion in research on the elderly (Weissert 1985b; Brecher and Knickman 1985). The search for ready solutions is intensified by the magnitude of the threat represented by the disease and is probably exacerbated by at least two other factors. First, the pervasive fragmentation of public funding for health and social services encourages the development of separate programs and administrative structures for different populations and services and discourages policy learning across these. Second, the absence of clear and coherent federal policy in the area of AIDS services (Lee and Arno 1986; Iglehart 1987; Lee and Benjamin 1987) also contributes to the problem, for state and local governments are under enormous fiscal, political, and moral pressure to respond quickly and effectively to the needs of those affected by the epidemic.

A number of what may be considered "guiding principles" have emerged among the most informed and thoughtful figures in the AIDS field regarding development of services that are responsive to the care needs of persons with AIDS, both acute and long term, and that are manageable in cost terms. These principles involve specific

solutions to the problem of organizing a cost-effective delivery system. They include controlling the utilization of hospital care; limiting the role of nursing home care; expanding the availability of home- and community-based services and of hospice care; and developing case management as a mechanism to coordinate the delivery of care. Each of these solutions, it turns out, has emerged in recent years in planning for the care of the elderly. Each will now be examined in light of experience in designing services for older Americans and potential implications for thinking about policy for AIDS care.

Controlling the Use of Inpatient Care

If any single theme has dominated policy analysis and research regarding health care for the elderly in the past two decades, it is that payment incentives and conventional medical practice have encouraged excessive utilization by older Americans of institutional forms of care, including inpatient hospital care and skilled nursing facility care. It has become axiomatic that the utilization of inpatient services can and must be reduced, both because some portion of it is unnecessary and because all of it is expensive. The dramatic rise between 1965 and 1983 in the cost of inpatient hospital stays under Medicare has led to reforms in Medicare reimbursement designed to shorten hospital stays and slow the rate of increase in hospital spending for the elderly (Lave 1984; Vladeck 1984). Medicare's hospital prospective payment system based on diagnosis-related groups (DRGs) is but the most visible of various federal, state, and private sector initiatives to control inpatient hospital costs.

Inpatient hospitalization is an accepted component of care for persons with AIDS, particularly in the early and latter stages of this complex and deadly disease. Considerable state and local attention is being given to increasing the access of persons with AIDS to specialized inpatient care (e.g., designated inpatient units) and to expanding the role of community hospitals in the provision of care. In San Francisco this has meant public efforts to enhance the availability of community hospital beds in order to ease demand on the county hospital. In New York this has taken the form of state funding for selected public and private (nonprofit, community) hospitals as specialized AIDS centers (Fox 1986).

These initiatives to improve availability of and access to inpatient beds have been accompanied by other, highly visible efforts to monitor and reduce the number of inpatient days for the average AIDS user of care (Crossley and Henry 1987; Luehrs, Orlebeke, and Merlis 1986). The desirability of early hospital discharge is justified for several interrelated reasons: (1) it will reduce the number of "administrative days" in which acute care beds are occupied by patients whose care needs can be met in other settings; (2) it may free a limited number of beds for other patients, particularly in county hospitals where demand may be overwhelming; and (3) more generally, early discharge is expected to moderate the overall cost of care.

A small but growing body of research on the costs of AIDS care suggests that as much as 90 percent of expenditures for persons with AIDS is consumed in the provision of inpatient services (Seage et al. 1986; Scitovsky, Cline, and Lee 1986). Recent research has also revealed wide variations among communities with respect to the average annual or lifetime costs associated with care for AIDS victims (Benjamin et al. 1986; Sisk 1987) and the percentage of costs associated with hospital care (Scitovsky et al. 1988). Suggested explanations for these variations inevitably point to differences among communities in the average number of hospitalizations and average inpatient lengths of stay for AIDS patients. The most visible of the community comparisons has been that involving New York and San Francisco; lower average costs in the latter city are attributed primarily to shorter average inpatient stays there, which in turn are linked to the wider availability of outpatient- and community-based service alternatives that may make prolonged hospitalizations unnecessary (Arno and Hughes 1987; Sisk 1987). Specific evidence regarding the role of community care alternatives will be separately addressed later in this article.

Several themes in the recent debate on the impact of Medicare prospective payment for the hospitalized elderly merit attention in the context of AIDS. First, the empirical evidence is still limited regarding the degree to which substantial savings can be achieved through efforts to reduce inpatient hospital use. Physicians are clearly willing to discharge their elderly patients from hospitals after a shorter length of stay than in the past, and average Medicare hospital stays have declined steadily in recent years. There are many other options available to hospitals facing pressures on length of stay, however, including increasing admissions and altering the assignment of diagnoses,

in order to counter the threat of a decline in revenues. More broadly, efforts to reduce hospital use may generate modest savings for public and private payers while shifting the burden of care (and its costs) to other payers, patients, and informal care providers.

Second, federal efforts to reduce Medicare inpatient stays have generated widespread alarm that the elderly are being discharged "quicker and sicker," i.e., before medically appropriate (Estes 1988; U.S. General Accounting Office 1986). Coherent debate over the actual extent of this phenomenon and its consequences is undermined by difficulties in marshalling adequate data on patient outcomes pre- and post-introduction of the Medicare prospective payment system in 1983 (Fink et al. 1987) and by problems in interpreting possible differences between cohorts of Medicare users over time (Neu and Harrison 1988). This debate has been further complicated by a third issue, one that has received relatively little attention, namely, the absence of precise and interpretable standards defining "appropriate" versus "excessive" medical care. Since uncertainty with respect to standards of care is undoubtedly greatest in the early phases of medical response to a new disease, this represents a potentially important problem in the effort to treat AIDS appropriately but with "minimum" utilization of inpatient settings (Volberding 1985). The Medicare "quicker and sicker" debate is so heated because illness and recovery are deeply personal concerns for which issues of cost are considered by many to be inappropriate. However much payers and providers are concerned with excessive use of inpatient care, the fact remains that where life-threatening illness is concerned, for surprisingly large numbers of people in times of illness, be it ever so expensive, there is no place like the hospital.

Finally, it is important to give more analytical attention to various factors that may affect the length (and cost) of inpatient AIDS stays. The most significant of these may be medical knowledge and norms regarding management of the disease, which are changing rapidly and which continue to vary across communities, as well as across hospitals, specialties, and individual physicians (Sisk 1987; Green et al. 1987). As knowledge of the disease has improved, hospital length of stay has declined in communities throughout the country, whether or not well-organized community services were available. The precise character and degree of differences in medical practice patterns for AIDS have not been well described, but generally have long been recognized

(Wennberg and Gittelsohn 1982; Wennberg 1984) and may affect relative success in the treatment of symptoms, development, and adoption of new treatment approaches (e.g., outpatient or home drug therapies), and attitudes/behavior more generally with respect to discharge planning and out-of-hospital care. In other words, differences in hospital length of stay across communities (and over time) may largely be the result of shifting practice styles, development of new treatment protocols, and variations in the rate of their dissemination.

Other factors may also affect community differences in the utilization of inpatient hospital beds by AIDS patients. Variations in patient mix may be associated with the incidence of particular opportunistic infections. There is some evidence, for example, that Kaposi's sarcoma, which is more common among male homosexual AIDS patients, requires less hospitalization than pneumocystis carinii pneumonia, which is more common among IV drug users with AIDS (Sisk 1987; Scitovsky, Cline, and Lee 1986). It is likely also that, on the average, gay males have higher incomes and stronger informal networks of social support than do IV drug users, and the availability of informal supports at home may be necessary (if not sufficient) for discharge to home from the hospital.

Finally, very little attention has been given to assessing the impact of community and hospital characteristics on differences in hospital stays for AIDS patients. The existence of regional and community differences in average hospital stays for the elderly and other patients is well documented (Health Care Financing Administration 1984; Ginsburg and Koretz 1983), but little analysis has been done to determine the extent to which AIDS care patterns mirror these larger differences. Incentives to discharge are likely to vary across hospitals; this is most obviously so when the comparison between an overcrowded public hospital highly reliant on Medicaid payment and a half-empty community hospital, most of whose patients have private third-party coverage, is considered. Most AIDS research that addresses hospital stays has been concerned with public hospitals (Andrulis et al. 1987), but nonpublic, community hospitals and prepaid health plans account for at least 60 percent of AIDS discharges in New York and San Francisco. The character and complexity of discharge incentives are likely to affect the probability that alternative services will substitute for inpatient days.

Hospitals also vary with respect to the organization of inpatient

care. There is some evidence, for example, that the presence of "dedicated" inpatient AIDS units is associated with shorter average patient stays (Fox 1986). Explanations of this pattern may well involve greater utilization of home and community services or lower use of intensive care, or both. The evidence needs to be considered, because the difference has important implications for public policy. More generally, what may be characterized as a societal preoccupation with the length of hospital stays should be balanced by efforts to identify and assess the relative impact of treatment protocols, patient mix, and community and hospital characteristics in determining hospital use for persons with AIDS.

Modifying the Use of Nursing Home Care

No issue related to health care and the elderly has been more visible than that involving the use of nursing home care by older Americans. Since the establishment of the Medicaid program in 1965 virtually created the nursing home industry in the following decade, critics have pointed to problems of rising costs, inappropriate placement, inadequate care, and ineffectual regulation associated with the nursing home industry (Kane and Kane 1978; Vladeck 1980; Institute of Medicine Committee on Nursing Home Regulation 1986). Because Medicaid pays for nearly one-half of all nursing home care, a primary objective of public policy for the elderly in recent years has been to reduce the utilization of these facilities through establishment of stronger certificate-of-need regulation, prospective nursing home reimbursement mechanisms, preadmission screening, development of alternative services, and related strategies. Recent efforts to expand availability of skilled nursing facility care for persons with AIDS need to be understood within the context of the experience of the elderly with nursing homes.

While Medicaid continues to be the dominant third-party payer for nursing home beds, issues involving Medicare may have special relevance to policy thinking related to AIDS and nursing home care. Medicare reimburses skilled nursing facilities for specified care provided to certain elderly beneficiaries following hospitalization. For a number of reasons, nursing homes generally have been reluctant to accept Medicare patients (Feder and Scanlon 1982). These reasons include administrative ones (e.g., separate paperwork requirements) and more

programmatic ones involving reimbursement rates, care requirements, and the state of the market. Despite the fact that Medicare reimburses nursing homes at a level considerably higher than Medicaid's, most facilities prefer to deal with the latter. From an industry viewpoint, state Medicaid programs involve predictable volume and procedures as well as chronically ill patients with relatively light care demands. Medicare, by contrast, involves the uncertainty and restrictiveness of Medicare fiscal intermediaries (Smits, Feder, and Scanlon 1982) along with sicker patients with more intensive and skilled care requirements. In effect, Medicare rates have not been set high enough to compensate nursing homes for the additional cost of dealing administratively with Medicare intermediaries and caring for Medicare beneficiaries.

The significance of this problem is exacerbated by the supply and demand characteristics of the current nursing home market. In part because public policy (federal and state) has sought to moderate the growth of nursing home beds and their utilization, the supply of beds in many states is not adequate to meet demand for them. As a result, some markets are characterized by excess demand (Scanlon 1980; Swan and Harrington 1986), a circumstance that permits nursing home operators to select the types of patients they admit and the payers with whom they deal. For the elderly this has meant that nursing homes in some markets have preferred lighter care and private-pay patients and have limited admissions to Medicaid-eligibles and to those likely to spend down to Medicaid eligibility (Feder and Scanlon 1980; Vladeck 1980), the primary categories into which many (or most) persons with AIDS are likely to fall (Intergovernmental Health Policy Project 1987; Pascal 1987).

Policy research has thus far been silent regarding the extent of actual demand for nursing home care among persons with AIDS. Factors such as age, sex, and social supports seem to be significant in determining the risk of nursing home entry among the elderly (Cohen, Tell, and Wallack 1986; Weissert and Scanlon 1983; Butler and Newacheck 1981); thus far, relatively little inquiry regarding who among persons with AIDS will need nursing home care has been evident. While the documentation is sparse, most providers and planners agree that at any given time a significant proportion of persons with AIDS (perhaps 10 to 25 percent) could appropriately utilize the care provided by skilled nursing facilities. At least three subgroups of such patients can be identified: persons with posthospital care needs; persons

who are near death and require hospice-type care; and those with dementia considered too difficult to care for at home.

Various issues involving AIDS worry the nursing home industry, including concerns about the response of their elderly patients and their families to a younger and stigmatized AIDS population, and the importance of these should not be minimized (Intergovernmental Health Policy Project 1987; Gebhardt 1986; Kerschner 1986). Yet, I would argue that the more fundamental issues are those that have confronted the elderly for two decades and for which public policy makers have yet to formulate adequate solutions. First, many nursing homes, even those called "skilled nursing facilities" (SNF), are not well prepared or eager to provide highly skilled care. Second, however expensive nursing homes may seem to budget watchers, the industry believes that even Medicare rates fail to cover their costs. Third, the continuing gap between supply and demand allows many nursing homes to select only those patients they wish to admit. Policy makers concerned about reducing the inpatient hospital costs of AIDS by substituting nursing home care, thus, are faced with the task of generating more SNF beds for this population. The most obvious strategies involve stimulating additional supply (e.g., in the form of dedicated AIDS facilities or dedicated AIDS units within general facilities) and setting special SNF rates for AIDS patients (Intergovernmental Health Policy Project 1987). Both approaches are likely to have a modest positive impact in the short run, but neither addresses those underlying issues involving nursing home care that have surfaced for the elderly, namely that governments have been reluctant to take the administrative and regulatory steps necessary to ensure that truly skilled care be provided by nursing homes, and that the industry itself has historically seemed unprepared and unwilling to provide such care.

Expanding the Use of Community Services

In no service arena have answers been sought more enthusiastically to problems regarding the appropriateness and costs of health care for the elderly than in home- and community-based services. The steady rise in expenditures by public and private insurers for hospital and nursing home care, evidence of inappropriate placement and inadequate

care in nursing homes, and growth in the number of elderly in the population, particularly the "old old" (Rosenwaike 1985; Soldo and Manton 1985; U.S. Bureau of the Census 1984), have led to several Medicare and Medicaid initiatives designed to provide noninstitutional services and to screen more carefully persons admitted to nursing homes (Kane and Kane 1978, 1987; Vladeck 1980; Hughes 1985). By expanding availability of and access to medical (e.g., home health care and adult day health care) and nonmedical (e.g., homemaker, personal care, and social day care) services provided outside of institutional settings, policy makers have sought to reduce utilization by the elderly of hospital and nursing home care and, thus, to reduce significantly the cost of health care for this population. For a time home- and community-based services were considered a panacea for the health care problems of the elderly, what has been described as a kind of "silver bullet" which would eliminate service delivery problems in a single shot (Brecher and Knickman 1985). In a similar manner those who think seriously about the provision of services to persons with AIDS have embraced home and community services as the key to providing cost-effective and appropriate care. Recent experience in developing such care for the elderly illuminates some of the complex issues involved when this course is pursued.

Underlying federal and state initiatives in the past decade to expand the provision to the elderly of home- and community-based care (hereafter referred to as "community care") have been two distinct but related arguments: first, that the length of hospital stays for acutely ill elderly can be reduced through the provision of skilled health care at home; and second, that utilization of nursing homes by chronically impaired older persons can be contained through provision of a range of community care services to persons living at home (Weissert 1985b; Kane and Kane 1987; U.S. General Accounting Office 1987). So much policy faith has been placed in community care for the elderly that the sobering lessons of a decade of experience, although clearly articulated and synthesized (Weissert 1985c; Hughes 1985), have only slowly been acknowledged or embraced within the field. A growing body of research on community care demonstration programs has produced some important findings with respect to the impact of home and community care services.

First, while there is some evidence that skilled nursing care at home may reduce hospital use for the younger elderly who are acutely

ill (Hughes 1985), there is very little evidence that community care affects hospital or nursing home utilization by the chronically ill elderly (U.S. General Accounting Office 1987; Clark 1987; Hedrick and Inui 1986; Kemper et al. 1986; Weissert 1985c; Connor and Greene 1983). In large part this is due to the enormous problems involved in targeting community care to those persons who would be heavy users of nursing home care (Capitman 1986; Weissert 1986). These problems make it difficult generally to demonstrate that community care averts or shortens institutional use. Second, when scrutinized carefully, community care provides only limited outcome benefits to the elderly. In other words, the advantages of receiving community care versus usual care are limited primarily to client and care-giver contentment and satisfaction but often do not include other health and social outcomes. Indeed, it has been argued that community care has functioned primarily as a supportive system for family caretakers (Weissert 1985b). Finally, the availability of community care has not reduced the costs of health care for the elderly; rather, use of these services frequently has been associated with higher overall utilization of services and greater total expenditures (Hughes et al. 1987; Hedrick and Inui 1986; Hughes 1985; Shaughnessy 1985).

In virtually every community where health care for persons with AIDS is being discussed in public forums, attention is now being directed toward developing outpatient and community care services designed to reduce costs through limiting the utilization of inpatient hospital care for AIDS. These include demonstration programs in nine communities supported by the Robert Wood Johnson Foundation (RWJ) through its "AIDS Health Services Program" (Fox 1986; Altman 1986; Wells 1987); demonstration initiatives in ten communities funded by the Health Resources and Services Administration (six of which also receive support from RWJ); state-authorized efforts in California, New York, and other states; and a small but growing number of Medicaid home- and community-based waiver programs, most notably those in New Jersey (New Jersey Department of Health 1987) and New Mexico (Green et al. 1987).

Community care is widely believed to be the key to reducing hospital use by persons with AIDS and thus to providing appropriate (indeed, more appropriate) care at a lower cost to public and private insurers and to patients and their loved ones. Although the experience of the elderly with community care raises serious questions about the

promise of this approach, some important differences exist that provide some basis for optimism regarding such care for persons with AIDS. Foremost is the fact that reduced use of nursing home care, which is a very elusive target, is not the goal of community care for AIDS; instead, it is lowering the number of hospital days. The probability of hospital use by persons with AIDS is greater than the probability of nursing home use by the elderly. On the face of it, targeting persons with AIDS for whom community care might substitute for hospital days thus seems far less problematic than does targeting care to older persons who otherwise would be confined to a nursing home. A small percentage of the elderly use nursing home services in any given year, and nearly two-thirds have stays of less than six months (Sekscenski 1987; Manheim and Hughes 1986). A majority of persons with AIDS are hospitalized at one, and often multiple, points in their illness; recent research suggests that the average number of hospitalizations per illness is from three to four times (Seage et al. 1986; Scitovsky, Cline, and Lee 1986). Furthermore, the fact that a hospitalization may involve costs/charges of \$600 to \$900 per day, while a nursing home stay costs only a fraction of that, enhances the likelihood that savings derived from the substitution of community care services for hospital days will be greater than those from substitution for nursing home days.

There are, nonetheless, reasons why evidence from the elderly experience merits further review and attention. It is certainly reasonable to argue that home health care and short-term skilled nursing facility care may substitute for the latter days of a hospital stay, and, indeed, this belief is widely shared by hospitals and their critics in explaining the drop in Medicare hospital length of stay in recent years. But the empirical evidence supporting this remains sparse, and the elderly experience suggests that patients are likely to use community services in addition to institutional ones rather than as substitutes for them. The case of San Francisco, often cited as the community care model for AIDS, illustrates the complexity involved in making the substitution case. Demonstrating that San Francisco has a better-developed community services system for AIDS and a shorter average hospital length of stay than New York is straightforward (Arno and Hughes 1987). What is more difficult is, first, demonstrating empirically that the former explains the latter and, second, replicating this experience across other communities (Sisk 1987).

Difficulties arise because the success of community care seems to be predicated on two assumptions. One is that home- and community-based service alternatives that will substitute for hospital care are, in fact, available. In San Francisco these have primarily taken the form of outpatient medical care and nonmedical residential and support services provided largely through community agencies and by volunteers. The availability of home health care has been limited and access to skilled nursing facility care virtually nonexistent. The second assumption is that the length of hospital stays is primarily determined by the availability of service alternatives and much less influenced by other factors, such as variations in case mix or practice patterns (Arno and Hughes 1987). As suggested earlier, relatively little attention has been given to examining questions that arise from this second assumption. For example, which specific home- and community-based services are expected directly to substitute for hospital days? Does substitution occur more often for patients in certain risk groups or for those with certain diagnoses? The latter may be important because there is evidence that hospital utilization and costs vary to some extent by diagnosis (Sisk 1987; Rubenstein et al. 1986; Hodgson and Kopstein 1984).

A recent review of extended inpatient stays in New Jersey, for example, suggests that "excessive" stays may be confined primarily to homeless, intravenous drug users with AIDS, since it is generally difficult to find residential facilities that will accept this population and it is impractical to provide home care to persons who may lack family care givers or any stable housing. Experience in New Jersey also suggests that the length of inpatient stays probably are more likely to be reduced if service alternatives are located within (or near) the inpatient facility rather than at a distance (Coopers and Lybrand, Inc. 1987). At the moment both of these arguments represent hypotheses generated from limited experience, but testing these and others holds promise for identifying empirically the problems to be addressed and solutions that may be effective. Experience with the elderly suggests that service substitution can occur for specified care to targeted subpopulations, and that broader (i.e., less targeted) approaches are unlikely to reduce utilization or costs (Kane and Kane 1987; Weissert 1986; Shaughnessy 1985).

Substitution of community care for persons with AIDS may also be more likely to occur at certain points in the course of the illness. This may be significant because hospitalizations seem to be concentrated

in the early and late stages of the illness. To what extent and under what conditions does the development of nonmedical supportive services enhance the likelihood of effective substitution? Certain forms of home health care for the elderly, for example, are considered impractical without informal care givers present in the home. Since informal care provided by volunteers has been a significant component of community care for all populations, but especially for persons with AIDS, it becomes important to "price out" the cost of these services when computing the true costs of this alternative care (Arno and Hughes 1987; Mor 1987; Paringer 1983).

Extending the Availability of Hospice Care

In little more than a decade the hospice movement in America has had a profound impact on policy thinking regarding care of the terminally ill, a majority of whom are elderly. The architects of hospice care emphasize pain and symptom control, the psychosocial needs of both patient and family, and the importance of continuity of care by an interdisciplinary care team (Mor 1987). Such was the appeal of the idea of hospice that after only a brief period of federal funding for demonstration programs and before results of evaluation studies were available, reimbursement for hospice services under Medicare was authorized by the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 and permanently reauthorized by the Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1986.

Since hospice services can be considered a subset of home- and community-based services, the primary appeal of hospice care to federal policy makers involves the promise of more appropriate care in alternative settings at costs lower than those associated with conventional institutional care. As with community care, excessive utilization of institutional (in this case, hospital) care is the primary target of the hospice movement, since traditional, intensive hospitalization is considered irrelevant and alienating to most dying patients with chronic disease. Although hospice care can be based within special hospital units or the community, the emphasis within the movement and in the Medicare legislation and regulations is clearly to limit the use of inappropriate inpatient services while substituting more relevant palliative care for the terminally ill.

Support for hospice care for persons with AIDS is growing among advocates for groups at high risk of contracting the disease, particularly gay advocates, as well as among hospice providers, and both sets of interests share a concern about appropriateness and quality of care and a commitment to the supportive environment associated with hospice care (Martin 1986). For federal and state officials, on the other hand, hospice services have become formalized as Medicare benefits for the elderly and other Title XVIII beneficiaries (and in some states as Medicaid benefits, most recently as part of state AIDS "waiver" applications), primarily because they are expected to yield sizable savings over traditional patterns of care, which have been shown to be very expensive in the last months of life (Lubitz and Prihoda 1984; Scitovsky 1984). Of course, hospice care is also expected to produce positive outcomes with respect to the quality of life of patients and their families. Recent research on the impact of hospice care for the elderly and others provides some basis for assessing the strength of these claims and may help us to anticipate some of the issues certain to confront hospice care for persons with AIDS.

In the most comprehensive review thus far of research on the outcomes of hospice care, Mor (1987) considers the impact of hospice services on various dimensions of the quality of life of those served and on the costs of care to those who finance it. Generally, the research suggests that while hospice appears to deliver the kind of services that patients and their families want, it is difficult to demonstrate that hospice users are much better off in specific ways than are nonhospice terminal patients. For example, results are mixed with respect to pain control, one of the central objectives of hospice care. It seems that the more sophisticated the study of pain control outcomes, moreover, the more likely are the findings to be mixed or to indicate little difference between hospice and nonhospice users (Mor 1987; Greer et al. 1986; Kane et al. 1984; Zimmer, Groth-Juncker 1984). In a similar manner, results are ambiguous regarding the impact of hospice care on the number and severity of other physical symptoms reported by the patient (Mor 1987; Greer et al. 1986). Research findings regarding patient psychosocial outcomes are somewhat less ambiguous, for they suggest that hospice care has no such positive outcomes unless explicit (and expensive) interventions are included and are targeted to the minority of patients and families likely to benefit from them (Mor 1987).

Data on the cost outcomes of hospice care are more encouraging, primarily because the last months of life represent a disproportionately expensive period in health care terms and one for which the cost-savings potential should be high. This potential derives from the opportunity to substitute relatively inexpensive home care for traditional hospital care and to control clinical patterns of care during hospitalization through an inpatient care (hospice) team. While the findings are somewhat mixed, the literature generally supports the conclusion that the home care hospice model is less costly than nonhospice care (Mor 1987; Mor and Kidder 1985), while the hospital-based hospice model seems to yield little or no savings. The lower costs of the home-based model are directly attributable to the relatively low utilization of inpatient days by home care patients. While this decline in hospital use is encouraging to those monitoring the costs of care, it raises an additional issue that has already confronted those doing research on the elderly.

Reduced hospital use is made possible because the burden (and cost) of care is shifted from the hospital staff (and third-party payers) to the family or other informal care providers in the home, with some supplementation by the hospice care program (Mor 1987; Greer et al. 1986). In effect, no cost savings to providers and payers would be achievable without the intense participation of the family, which in one national study provided an average of 10 hours of direct care daily to dying family members (Mor 1987). Such commitment on the part of family and friends tends to come at a price, however, both in terms of direct and out-of-pocket expenses for care and diminished earnings from reduced labor-force participation (Stone, Cafferata, and Sangl 1987; Paringer 1983).

The Medicare hospice experience suggests several themes of relevance to planning for the care of persons with AIDS. In an era of careful monitoring of health care costs, the selling of hospice care requires making the case for its cost-effectiveness; because the evidence (at least for the home-based hospice model) is generally positive, this is far less difficult in this case than for other community care alternatives. In order to avoid being judged solely by this cost standard, however, it is necessary that research attention be directed at elaborating and testing other patient and informal care-giver outcomes specifically relevant to AIDS.

It is apparent from Medicare research that there are subsets of the

elderly for whom hospice services are important and beneficial, and it is important to specify more fully who these subsets are and to devise strategies for targeting services to them. The conviction of hospice advocates regarding the benefits of hospice care to persons with AIDS may not be matched fully, however, by that of victims of the disease or representatives of AIDS-related advocacy groups. The reasons for this are complex, and in part are due to the conflicts between accepting the terminal status associated with AIDS and sustaining the hope that experimental drugs like AZT will permit persons (generally young) to survive despite predicted short life expectancies. Models of hospices that can accommodate experimental drugs may need to be developed if hospice care is to generate widespread demand among persons with AIDS.

The relation between hospice and informal care for persons with AIDS may prove more complex than for the terminally ill elderly, and this may have significant implications for the longer-run viability of the hospice care option. Informal support for the elderly depends in large measure on the efforts of female spouses and adult daughters (Stone, Cafferata, and Sangl 1987; Doty 1986), most of whom live in the same community if not in the same household. Despite the fact that the AIDS crisis in several American cities has generated a heroic response on the part of the male homosexual community and others, too little is known about the social support systems of major risk groups and about the durability of volunteer efforts to be certain that the considerable foundation of informal care needed to sustain hospice care will be available over time for persons with AIDS. It should be noted that this issue is hardly unknown to the elderly, many of whom live alone or with frail spouses and thus are unlikely to qualify for hospice care because of inadequate informal supports.

Introduction of Case Management Services

Emphasis on the development of an integrated system of outpatient-, home- and community-based services for AIDS patients has been accompanied by attention to mechanisms for facilitating service integration, most notably case management (University of Washington Institute on Aging 1987; Capitman, Haskins, and Bernstein 1986; Beatrice 1981). Case management services, whether provided by phy-

sicians or other health care professionals, are designed to assure more appropriate and timely services to patients, to reduce the coordination costs faced by patients and their families, and to lower overall expenditures for health care because more appropriate and less costly (usually noninstitutional) services are provided (Spitz 1987).

Growing enthusiasm for AIDS case management comes at a time when findings from research on case management services for the elderly and others are becoming available. That research generally grew out of conviction in the late 1970s that case management was the answer to many of the problems confronting policy makers concerned with long-term care for the elderly. The results of this research raise some important issues regarding the effectiveness of this intervention.

The National Long-term Care Demonstration, known otherwise as the "Channeling Demonstration," was initiated in 1980 to assess the impact of comprehensive case management in allocating community services appropriately and cost effectively to the frail elderly in need of long-term care. Results of an evaluation of these demonstration programs indicate that case-management services reduce the unmet needs reported by clients, enhance client and care-giver confidence and satisfaction, and increase the use of community-based, noninstitutional services. Case management had little impact on client health and functioning, however, and little or no effect on the use of institutional services (Kemper et al. 1986). Generally, provision of case-management services increased the cost of care provision without producing commensurate reductions in the utilization of what are considered inappropriate services, specifically hospital and nursing home care. Adding case management to an enhanced service package of home and community services does little to foster the service substitution that package is intended to produce. Other research suggests that targeting case-management resources to specific subsets of those at-risk may produce some positive outcomes for patients, although the costs of care will not be reduced (Morris et al. 1987; Ruchlin et al. 1987).

These recent findings are consistent with, if not more optimistic than, other research on case management for the elderly and others. Hughes (1985) reviewed a range of studies involving community care for the elderly and concluded that case management encourages increased utilization of noninstitutional services, but does not affect the use of institutional service and results in equal or higher health care costs. In a study of case management for the chronically mentally ill, Franklin

et al. (1987) concluded that those who received case management utilized more services, including hospital care, and cost more without concomitant improvements in quality of life.

Recent research on case-management efforts within the Medicaid program (Spitz 1987) and elsewhere highlights two significant paradoxes concerning the substance of this approach to health care delivery and the priorities assigned to it. First, case management continues to attract enthusiastic attention as a solution to various systemic problems in designing services for needy populations; yet, there persists widespread confusion and disagreement regarding precisely what case management is and what it is intended to achieve. Second, the popularity of case-management approaches has grown in proportion to its association in the eyes of policy makers with cost-containment goals, despite mounting evidence that case management increases the cost of service provision rather than reducing it.

Case-management approaches should be an essential element of a comprehensive and planned service approach to the AIDS epidemic. To the extent that informed case-management professionals are able to assess care needs and to plan, arrange, and monitor the provision of services, the development of case management should contribute to rationalizing service delivery to and improving care received by persons with AIDS. Yet, the success of case management depends upon the emergence of some consensus regarding its functional definition, its policy goals, and the distribution of authority among professions or disciplines in its implementation. Among the definitional issues that must be addressed is the extent to which case managers are confined to gaining access to and coordinating services already available in the community or are provided a pool of additional funding with which to purchase services to fill gaps in existing programs (Kemper et al. 1986). Among issues related to goals is the priority to be given to access versus efficiency, an issue that can often pit advocates for patient groups against those who pay for patient care. Where no agreement exists regarding goal priorities, case-management programs will be expected to enhance access to appropriate services, whatever the cost, as well as to monitor the allocation of resources in order to contain the costs of care. Questions of professional roles abound in this arena as well, with physicians, nurses, social workers, and "interdisciplinary teams" variously defined as the appropriate locus of case-management authority. As AIDS case-management efforts emerge

in states like California and New York, debate over this latter issue has been at times heated. More generally, the provision of case-management services requires additional resources, and it is important to consider which outcomes are being pursued in order to justify expenditures that might otherwise purchase direct medical and social services.

Conclusion

Like many medical conditions affecting the elderly, AIDS is chronic and debilitating. Like those conditions among the elderly that require intensive and costly care—such as renal failure—AIDS necessitates care that can be complex and relatively expensive, although for a variety of reasons these costs seem to be declining (Sisk 1987; Scitovsky, Cline, and Lee 1986). Major themes in policy thinking regarding care of the elderly have been mirrored by recent planning for AIDS care; this has involved the design of a service system that permits persons with AIDS to stay out of the hospital, remain at home, and function independently in the community for as long as possible.

Findings from research on the elderly not only raise important issues relevant to AIDS but also may provide a basis for fresh thinking about the development of service models for the care of persons with AIDS. Foremost, we have learned that where fiscal criteria alone drive the development of policy, considerable burden falls on those advocating the expansion of given service solutions to provide evidence for their cost effectiveness. The experience in aging suggests that evidence to support such claims is difficult to generate because most innovations are not cost effective or are so only for subsets of a given population. This “cost-effectiveness trap” (Weissert 1985b) can only be avoided by developing other criteria by which service reforms can be justified. Examples of such criteria include patient preferences, the preferences of family and other care givers, as well as other outcome criteria such as benefits associated with reinforcing existing informal support networks.

There is considerable anecdotal evidence that most persons with AIDS prefer to reside at home or in noninstitutional settings that maximize their freedom, rather than in hospitals and nursing homes. Experiences with the elderly suggest that care provided at home and in the community reinforces care provided informally by family and

friends, who prefer direct-service assistance to other forms of government aid like cash payments or tax allowances (Doty 1986). More data are needed regarding the functions case management may play for persons with AIDS or their informal care givers. Given the complexity of the disease and the wide range of health and social services needed to manage it, it seems reasonable to assume that most persons and their families would prefer professional assistance in planning for, monitoring, and interpreting their care needs rather than assuming full responsibility themselves for coordinating relationships with care providers. Systematic data on preferences regarding service planning and coordination of persons with different demographic and disease characteristics would also provide additional insights about target groups and situations for which case-management services are needed.

In considering the role of inpatient hospital and nursing home care for AIDS, data on client and care giver preferences would shed some needed light on two important issues. First, discussions with medical providers indicate a growing concern in some places with what is perceived as a preoccupation with community care and a failure to acknowledge a central role for medical care in the management of the disease. Given the fact that the "problem" with AIDS care is widely believed to be excessive hospitalization and medicalization and a failure to understand the chronic-care requirements of the disease course, this new concern about the role of medical care is not without irony. As suggested earlier, there may be situations in which hospitalization (or an outpatient clinic visit) are important not only for medical reasons but because informal care givers may be overwhelmed by the burdens of care, especially its "life and death" elements. Aging research is just starting to address questions regarding the types and timing of formal care that are needed to sustain informal care. It seems essential with respect to AIDS to study the disease course in terms of the needs and preferences of family members, friends, volunteers, and nonmedical professionals and to identify specific circumstances in which medical intervention may be essential.

The second issue for which preference data is needed involves the place of nursing homes in the care of AIDS. What little attention has been given to this has involved identifying industry obstacles (e.g., reimbursement, staff attitudes) to increasing the availability of beds for AIDS care. As suggested earlier, almost no attention has been paid to the demand side of this equation, namely the attitudes

of persons with AIDS (PWAs) and their care givers toward nursing home care and specific situations in the disease course when such care may be appropriate. There is anecdotal evidence that nursing home care may be shunned by homosexual men in some communities; there is also evidence that informal care givers may view nursing homes as a necessary option for patients with dementia. Even less is known about the care preferences of persons in other risk groups, especially intravenous drug users. A great deal more data on situational preferences is needed before any reasonable estimate can be made of the demand for nursing home and other services.

Virtually all of the discussion thus far has concerned ways in which experience with the elderly can inform the development of long-term care policy for AIDS. This should not blind us to another, equally important, theme involving the significant impact that policy thinking and activity regarding AIDS is likely to have on public policy regarding long-term care for the elderly and other chronically disabled populations. At the least, policy formulation and development for AIDS services is stimulating many who think about aging to broaden and sharpen their perspectives on long-term care.

Important efforts have very recently been made to examine chronic illness in terms of common care needs of the elderly and younger disabled adults as well as the elderly and chronically ill children. Recent assessments of the impact of Medicare prospective payment have drawn new attention to the critical interdependencies between acute care and community services for functionally dependent persons following hospitalization. The AIDS epidemic may now be providing a further boost to debate regarding the adequacy of health care systems in those states and communities where the disease is most visible and may be focusing new attention on the idea of a "continuum of care" that bridges traditional boundaries between acute and long-term care and that is available for the chronically ill, whatever their age or eligibility category. The public health crisis represented by AIDS has highlighted the reluctance of public and private payers to underwrite long-term care services outside the nursing home for any population and brought into sharp relief the gap between what we know about the development and management of a continuum of care for the chronically ill and the political will required to support a range of institutional, community, and home-based services. The visibility of AIDS, on the other hand, may generate sufficient broad-based interest

in chronic illness and long-term care to force a systematic federal policy response to the care needs of various populations, needs that are currently addressed in a piecemeal and inadequate fashion.

References

- Altman, D. 1986. More Effective and Less Costly AIDS Health Services. *Caring* 5:52-55.
- Andrulis, D.P., V.S. Beers, J.D. Bentley, and L.S. Gage. 1987. The Provision and Financing of Medical Care for AIDS Patients in U.S. Public and Private Teaching Hospital. *Journal of the American Medical Association* 258:1343-46.
- Arno, P.S. 1986. The Nonprofit Sector's Response to the AIDS Epidemic: Community-based Services in San Francisco. *American Journal of Public Health* 76:1325-30.
- Arno, P.S., and R.G. Hughes. 1987. Local Policy Responses to the AIDS Epidemic: New York and San Francisco. *New York State Journal of Medicine* 87:264-72.
- Beatrice, D.F. 1981. Case Management: A Policy Option for Long-term Care. In *Reforming the Long-term Care System*, ed. J.J. Callahan and S.S. Wallack. Waltham, Mass.: University Health Policy Consortium.
- Benjamin, A.E., P.R. Lee, A.E. Scitovsky, L. Swig, M. Cline, and H. Wolfe. 1986. *The Cost of Care of AIDS in California: Interim Report I*. San Francisco: Institute for Health Policy Studies.
- Bishop, C.E. 1986. Living Arrangements Choices of Elderly Singles: Effects of Income and Disability. *Health Care Financing Review* 7:65-73.
- Branch, L.G., and A.M. Jette. 1981. The Framingham Disability Study: I. Social Disability among the Aging; II. Physical Disability among the Aging. *American Journal of Public Health* 71:1202-12.
- Branch, L.G., S. Katz, K. Kniepman, and J.A. Papsidero. 1984. A Prospective Study of Functional Status among Community Elders. *American Journal of Public Health* 74:266-68.
- Brecher, C., and J. Knickman. 1985. A Reconsideration of Long-term Care Policy. *Journal of Health Politics, Policy and Law* 10:245-73.
- Butler, L.H., and P.W. Newacheck. 1981. Health and Social Factors Relevant to Long-term Care Policy. In *Policy Options in Long-term Care*, ed. J. Meltzer, F. Farrow, and H. Richman, 38-75. Chicago: University of Chicago Press.
- Capitman, J.A. 1986. Community-based Long-term Care Models,

- Target Groups, and Impacts on Service Use. *Gerontologist* 26:389-97.
- Capitman, J.A., B. Haskins, and J. Bernstein. 1986. Case Management Approaches in Community-oriented Long-term Care Demonstrations. *Gerontologist* 26:398-404.
- Clark, R.F. 1987. The Costs and Benefits of Community Care: A Perspective from the Channeling Demonstration. *Pride Institute Journal of Long-term Home Health Care* 6:3-13.
- Cohen, M.A., E.J. Tell, and S.S. Wallack. 1986. The Lifetime Risks and Costs of Nursing Home Use among the Elderly. *Medical Care* 24:1161-72.
- Commonwealth Fund Commission on Elderly People Living Alone. 1987. *Old, Alone and Poor: A Plan for Reducing Poverty among Elderly People Living Alone*. Baltimore, Md.: Commonwealth Fund Commission.
- Connor, M.J., and S.B. Greene. 1983. Should Extended Care Following Hospitalization Be Encouraged? *Inquiry* 20:258-63.
- Coopers and Lybrand, Inc. 1987. *An Evaluation of AIDS Treatment Sites for Alternative Levels of Care: A Report to the New Jersey Health Care Facilities Financing Authority*. New York.
- Crossley, K., and K. Henry. 1987. AIDS: Implications for Long-term Care. *Clinical Report on Aging* 1:1-6.
- Doty, P. 1986. Family Care of the Elderly: The Role of Public Policy. *The Milbank Quarterly* 64:34-75.
- Estes, C.L. 1988. Cost Containment and the Elderly: Conflict or Challenge? *Journal of the American Geriatric Society* 36:68-72.
- Feder, J., and W. Scanlon. 1980. Regulating the Bed Supply in Nursing Homes. *Milbank Memorial Fund Quarterly/Health and Society* 58:54-88.
- . 1982. The Underused Benefit: Medicare's Coverage of Nursing Home Care. *Milbank Memorial Fund Quarterly/Health and Society* 61:604-32.
- Fink, A., A.L. Siu, R.H. Brook, R.E. Park, and D.H. Solomon. 1987. Assuring the Quality of Health Care for Older Persons. *Journal of the American Medical Association* 258:1905-08.
- Fox, D.M. 1986. AIDS and the American Health Policy: History and Prospects of a Crisis of Authority. *The Milbank Quarterly* 64:7-33.
- Franklin, J.L., B. Solovitz, M. Mason, J.R. Clemons, and G.E. Miller. 1987. An Evaluation of Case Management. *American Journal of Public Health* 77:674-78.
- Gebhardt, R.B. 1986. Should Nursing Homes Take AIDS Patients? *Nursing Homes* 35:13-15.

- Ginsburg, P.B., and D.M. Koretz. 1983. Bed Availability and Hospital Utilization: Estimates of the 'Roemer Effect.' *Health Care Financing Review* 5:87-92.
- Green, J., M. Singer, N. Wintfeld, K. Schulman, and L. Passman. 1987. Projecting the Impact of AIDS on Hospitals. *Health Affairs* 6:19-31.
- Greer, D.S., V. Mor, J.N. Morris, S. Sherwood, D. Kidder, and H. Birnbaum. 1986. An Alternative in Terminal Care: Results of the National Hospice Study. *Journal of Chronic Disease* 39:9-26.
- Health Care Financing Administration. 1984. *Medicare Program Statistics: Selected State Data, 1978-1982*. Baltimore, Md.
- Hedrick, S.C., and T.S. Inui. 1986. The Effectiveness and Cost of Home Care: An Information Synthesis. *Health Services Research* 20:851-80.
- Hodgson, T.A., and A.N. Kopstein. 1984. Health Care Expenditures for Major Diseases in 1980. *Health Care Financing Review* 5:1-12.
- Hughes, S.L. 1985. Apples and Oranges: A Critical Review of Evaluations of Community-based Long-term Care. *Health Services Research* 20:461-88.
- Hughes, S.L., L.M. Manheim, P.L. Edelman, and K.J. Conrad. 1987. Impact of Long-term Home Care on Hospital and Nursing Home Use and Cost. *Health Services Research* 22:19-47.
- Iglehart, J.K. 1987. Financing the Struggle against AIDS. *New England Journal of Medicine* 317:180-84.
- Institute of Medicine Committee on Nursing Home Regulation. 1986. *Improving the Quality of Care in Nursing Homes*. Washington: National Academy Press.
- Intergovernmental Health Policy Project. 1987. *AIDS: A Public Health Challenge: Volume 2: Managing and Financing the Problem*. Washington: U.S. Public Health Service.
- Kane, R.L., and R.A. Kane. 1978. Care of the Aged: Old Problems in Need of New Solutions. *Science* 200:913-19.
- . 1987. *Long-term Care: Principles, Programs, and Policies*. New York: Springer.
- Kane, R.L., J. Wales, L. Bernstein, A. Leibowitz, and S. Kaplan. 1984. A Randomized Controlled Trial of Hospice Care. *Lancet* 1:890-94.
- Kemper, P.R., S. Brown, G.J. Carcagno, R.A. Applebaum, J.B. Christianson and others. 1986. *The Evaluation of the National Long-term Care Demonstration: Final Report*. Washington: U.S. Department of Health and Human Services.
- Kerschner, P. 1986. AIDS and Long-term Care: Problems and Possibilities. *Discharge Planning Update* 6:11-14.

- Lave, J.R. 1984. Hospital Reimbursement under Medicare. *Milbank Memorial Fund Quarterly/Health and Society* 61:251-68.
- Lee, P.R. 1986. AIDS: Allocating Resources for Research and Patient Care. *Issues in Science and Technology* 2:66-73.
- Lee, P.R., and P.S. Arno. 1986. The Federal Response to the AIDS Epidemic. *Health Policy* 6:259-67.
- Lee, P.R., and A.E. Benjamin. 1984. Health Policy and the Politics of Health Care. In *Introduction to Health Services*, ed. S.J. Williams and P. Torrens, 461-80. New York: John Wiley.
- . 1987. *The Cost of AIDS: The Evidence and the Issues*. San Francisco: Institute for Health Policy Studies, University of California.
- Lubitz, J., and R. Prihoda. 1984. The Use and Costs of Medicare Services in the Last Two Years of Life. *Health Care Financing Review* 5:117-31.
- Luehrs, J., E. Orlebeke, and M. Merlis. 1986. The Role of Medicaid in Treating Those with AIDS. *Public Welfare* 34:20-28.
- Manheim, L.M., and S.L. Hughes. 1986. Use of Nursing Homes by a High-risk Long-term Care Population. *Health Services Research* 21:161-76.
- Manton, K.G., and B.J. Soldo. 1985. Dynamics of Health Changes in the Oldest Old: New Perspectives and Evidence. *Milbank Memorial Fund Quarterly/Health and Society* 63:206-85.
- Martin, J.P. 1986. The AIDS Home Care and Hospice Program: A Multidisciplinary Approach to Caring for Persons with AIDS. *American Journal of Hospice Care* 1986:35-37.
- Mor, V. 1987. *Hospice Care Systems: Structure, Process, Costs, and Outcome*. New York: Springer.
- Mor, V., and D. Kidder. 1985. Cost Savings in Hospice: Final Results of the National Hospice Study. *Health Services Research* 20:407-21.
- Morris, J.N., C.E. Gutkin, H.S. Ruchlin, and S. Sherwood. 1987. Housing and Case-managed Home Care Programs and Subsequent Institutional Utilization. Boston: Hebrew Rehabilitation Center for Aged.
- Neu, C.R., and S.C. Harrison. 1988. *Posthospital Care before and after the Medicare Prospective Payment System*. Santa Monica: Rand Corp.
- New Jersey Department of Health. 1987. *AIDS in New Jersey*. Trenton.
- Paringer, L. 1983. *The Forgotten Costs of Informal Long-term Care*. Washington: Urban Institute.
- Pascal, A. 1987. *The Costs of Treating AIDS under Medicaid: 1986-1991*. A Rand note N-2600-HCFA. Santa Monica: Rand Corp.
- Rosenwaike, I. 1985. A Demographic Portrait of the Oldest Old. *Milbank Memorial Fund Quarterly/Health and Society* 63:187-205.

- Rubenstein, L.Z., K.R. Josephson, G.D. Wieland, and R.L. Kane. 1986. Differential Diagnosis and Utilization Patterns among Clinical Subgroups of Hospitalized Geriatric Patients. *Health Services Research* 20:881-95.
- Ruchlin, H.S., J.M. Morris, C.E. Gutkin, and S. Sherwood. 1987. Expenditures for Institutional and Community-based Services by a Cross-section of Elderly Living in the Community. Boston: Hebrew Rehabilitation Center for Aged.
- Scanlon, W.A. 1980. A Theory of the Nursing Home Market. *Inquiry* 17:25-41.
- Scitovsky, A.A. 1984. "The High Cost of Dying": What Do the Data Show? *Milbank Memorial Fund Quarterly/Health and Society* 62:591-608.
- Scitovsky, A., A.E. Benjamin, P.R. Lee, M. Cline, L. Swig, and H. Wolfe. 1988. *The Cost of Care of AIDS in California: Interim Report III*. San Francisco: Institute for Health Policy Studies.
- Scitovsky, A.A., M. Cline, and P.R. Lee. 1986. Medical Care Costs of Patients with AIDS in San Francisco. *Journal of the American Medical Association* 256:3103-06.
- Seage, G.R., S. Landers, M.A. Barry, J. Groopman, G.A. Lamb, and A.M. Epstein. 1986. Medical Care Costs of AIDS in Massachusetts. *Journal of the American Medical Association* 256:3107-09.
- Sekscenski, E.S. 1987. *Discharges from Nursing Homes: Preliminary Data from the 1985 National Nursing Home Survey*. Advance data no. 142. Washington: National Center for Health Statistics.
- Shaughnessy, P.W. 1985. Long-term Care Research and Public Policy. *Health Services Research* 20:489-99.
- Sisk, J.E. 1987. The Costs of AIDS: A Review of the Estimates. *Health Affairs* 6:5-21.
- Smits, H.L., J. Feder, and W. Scanlon. 1982. Medicare's Nursing Home Benefit: Variations in Interpretation. *New England Journal of Medicine* 307:855-62.
- Soldo, B.J., and K. Manton. 1985. Health Status and Service Needs of the Oldest Old: Current Patterns and Future Trends. *Milbank Memorial Fund Quarterly/Health and Society* 63:286-319.
- Spitz, B. 1987. National Survey of Medicaid Case Management. *Health Affairs* 6:61-70.
- Stone, R., G.L. Cafferata, and J. Sangl. 1987. Caregivers of the Frail Elderly: A National Profile. *Gerontologist* 27:616-26.
- Swan, J.H., and C. Harrington. 1986. Estimating Undersupply of Nursing Home Beds in States. *Health Services Research* 21:57-83.
- U.S. Bureau of the Census. 1984. Projections of the Population of

- the United States by Age, Sex and Race: 1983 to 2080. *Current Population Reports*, series P-25, no. 952. Washington.
- U.S. General Accounting Office. 1986. *Post-Hospital Care: Efforts to Evaluate Medicare Prospective Payment Effects Are Insufficient*. GAO/PEMD-86-10. Washington.
- . 1987. *Medicaid: Determining Cost Effectiveness of Home and Community-based Services*. Washington.
- University of Washington Institute on Aging. *Improving Access for Elders: The Role of Case Management*. Seattle.
- Vladeck, B.C. 1980. *Unloving Care: The Nursing Home Tragedy*. New York: Basic Books.
- . 1984. Comment on 'Hospital Reimbursement under Medicare.' *Milbank Memorial Fund Quarterly/Health and Society* 62:269–78.
- Volberding, P.A. 1985. The Clinical Spectrum of the Acquired Immunodeficiency Syndrome: Implications for Comprehensive Patient Care. *Annals of Internal Medicine* 103:729–33.
- Weissert, W.G. 1982. *Size and Characteristics of the Noninstitutionalized Long-Term Care Population*. Washington, DC: The Urban Institute.
- . 1985a. Estimating the Long-term Care Population: Prevalence Rates and Selected Characteristics. *Health Care Financing Review* 6:83–91.
- . 1985b. Home and Community-based Care: The Cost-Effectiveness Trap. *Generations* 10:47–50.
- . 1985c. Seven Reasons Why It Is So Difficult to Make Community-based Long-term Care Cost Effective. *Health Services Research* 20:423–33.
- . 1986. Hard Choices: Targeting Long-term Care to the "At Risk" Aged. *Journal of Health Politics, Policy and Law* 11:463–81.
- Weissert, W.G., and W. Scanlon. 1983. *Determinants of Institutionalization of the Aged*. Washington: Urban Institute.
- Wells, J.A. 1987. Grant Watch: Foundation Funding for AIDS Programs. *Health Affairs* 6:113–23.
- Wennberg, J.E. 1984. Dealing with Medical Practice Variations: A Proposal for Action. *Health Affairs* 3:6–32.
- Wennberg, J.E., and A. Gittelsohn. 1982. Variations in Medical Care among Small Areas. *Scientific American* 246:120–34.
- Zimmer, J.G., A. Groth-Juncker, and J. McCusker. 1984. Effects of a Physician-led Home Care Team on Terminal Care. *Journal of the American Geriatric Society* 32:288–92.

Address correspondence to: A.E. Benjamin, Institute for Health and Aging, Room N631, University of California, San Francisco, Third and Parnassus Avenues, San Francisco, CA 94143-0646.