

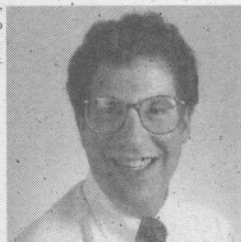


Risk in Perspective

The Human and Economic Costs of AIDS Therapies

"Gains in survival involve an explicit trade of cost and quality of well-being in exchange for quantity of life."

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The care of patients with HIV and AIDS presents the medical profession and the public with a tangled web of competing obligations to prolong survival, to improve quality of life, to contain costs, and to promote equity. Often, there is an irreconcilable conflict between the clinician's duty to do what is best for the patient and the public policy maker's obligation to promote the collective safety and well being.

This issue of Risk in Perspective explores some fundamental questions of scarce resource allocation and priority setting in the health sector against a backdrop of AIDS and HIV illness.

Improved Survival, Increased Cost

AIDS statistics paint the picture of an epidemiological, social, and economic disaster. According to the Centers for Disease Control and Prevention, there have now been over 440,000 AIDS cases reported in the United States. In addition, an estimated 1 million Americans are believed to be infected with HIV.

In the face of this tragedy, there is some good news. Mounting evidence suggests that survival is improving in people with HIV. From 1985 to the present, the median survival time from AIDS diagnosis is estimated to have risen from 11 to 30 months. Progress is generally attributed to earlier detection of disease, more comprehensive and effective clinical care, drug therapies (such as AZT) that slow the deterioration of the human immune system, and medications that prevent and treat the major opportunistic infections that take advantage of the body's weakened defenses.

Improved survival fuels the hope that HIV illness may one day be treated as a persistent, chronic condition. Yet, the gains that have been made to date in reducing AIDS-related morbidity and mortality come at a price. Most experts agree that the lifetime direct medical costs of HIV illness and AIDS have grown more than 50% in real terms since 1985. Moreover, existing therapies are generally associated with serious medical side-effects and toxicities. Gains in survival, there-

fore, involve an explicit trade of cost and quality of well-being in exchange for quantity of life.

Progress in reducing AIDS-related morbidity and mortality imposes another, less obvious burden: increased exposure to "competing" risks. As patients live longer with more advanced immune dysfunction, previously rare opportunistic infections are becoming more common. For example, the success of prophylaxis and therapy in controlling *Pneumocystis carinii* pneumonia incidence and death means that many more patients are now progressing to *Mycobacterium avium* complex, *cytomegalovirus*, *toxoplasmosis*, and fungal infections than ever before. These end-stage complications generally carry with them seriously increased levels of discomfort, disability, as well as economic cost.

The policy dilemma is clear. Preventing the early symptoms of AIDS buys marginal improvements in life expectancy while exposing patients and society to a host of potentially painful and expensive downstream consequences. At a time of serious budgetary compressions and continuing spread of infection nationwide, it is important to ask whether the benefits of AIDS therapies justify the many alternative, life-prolonging opportunities forgone.

Irreconcilable differences

The question of priority setting and resource allocation among competing AIDS interventions boils down to a tragic choice that pits the interests of the individual against those of the general population. At the heart of the dilemma is an irreconcilable tension between two deeply rooted human convictions.

Pulling us in one direction is the ethical sense of duty to the identified life in peril, a conviction that has been labeled the "Rule of Rescue." It is a natural human predisposition to focus on highly visible individuals in danger, even when actions to rescue them risk the potential loss of a greater number of unseen, "statistical" lives. This inclination is what drives us to spend tens of

thousands of dollars plucking little girls from the bottoms of wells, even when we know that a similar expenditure could prevent the deaths of many more little girls were it devoted either to building fences around wells or to vaccination programs and improved automobile safety. The Rule of Rescue is a powerful force on human behavior. Indeed, at the individual clinician's level, it may be impervious to logical argument and considerations of economic cost.

Pulling us in the other direction is a utilitarian conviction that society ought to set its priorities and allocate its scarce resources in a manner that confers the greatest possible benefit, subject to resource constraints. Rising health costs, growth in the size of the uninsured population, and the proliferation of new medical technologies have all served to heighten social concern with issues of fairness and efficiency in the health sector. A more informed, more sophisticated, and more distrustful public detects some perversity and unfairness in the Rule of Rescue when applied at the population level. Simply stated, we cannot afford to provide every possible form of care, to every patient in need, without regard to severity, equity, or the alternatives forgone.

As a basis for global resource allocation, the Rule of Rescue is both inequitable and financially disastrous. At the patient care level, however, it will almost invariably trump the more "rational" utilitarian view. We need only look at the recent debate over the Medicaid rationing plan in Oregon to see how painful the tension between these two mutually incompatible imperatives can be. How then, should this delicate balance be managed?

Formal analysis as process

The first step is to acknowledge that any priority setting mechanism for health interventions is likely to encounter stiff public and professional opposition unless its results can be shown to have face validity. In other words, the final priority rankings must satisfy basic, intuitive credibility requirements such as the Rule of Rescue.

The second step is to embrace formal policy evaluation as means of identifying and evaluating the inequities and inefficiencies that are implicit in any subjective ranking process. Cost-effectiveness and risk-benefit analysis aim to portray decisions in terms of both the benefits conferred and the benefits forgone. By holding the consequences of choice up to public scrutiny, they can help people to understand the human and economic costs of adhering to the Rule of Rescue and, thus, promote a fairer, more reasoned approach to priority setting.

Viewed in this light, the purpose of formal evaluation is emphatically not to supplant the patient, the physician, or the politician as the

ultimate decision maker. Nor is it to question the legitimate role played by the "gut feel" as a basis for choice. Rather, it is to provide information in the service of a subjective—but reasoned—decision making process.

Medical Decision Science at HCRA

It is in the spirit of informing the debate over AIDS priorities that researchers at the Harvard Center for Risk Analysis are currently working to identify those medicines that produce the greatest attainable reduction in HIV- and AIDS-related mortality and morbidity for any given funding level. An interdisciplinary team of decision analysts, clinicians, epidemiologists, and biostatisticians has been assembled to assess the impact of prophylaxis and treatment on cost, quality of life, and survival in patients with HIV illness and AIDS. Using the methods of cost-effectiveness analysis and mathematical modeling, the project team is considering such issues as: the comparative impact of aggressive prevention programs versus reactive treatment strategies; identification of "optimal" treatment protocols; formal specification of the quality/quantity trade-off; and the cost-effectiveness of preventing AIDS complications in light of available, life-prolonging alternatives.

This issue of Risk in Perspective introduces readers to a new area of study for the Harvard Center for Risk Analysis. Since the early 1970's, the Harvard School of Public Health has been a pioneer in the application of risk-benefit and cost-effectiveness analyses to medical practices. In the fall of 1994, the School's faculty in medical decision sciences joined HCRA in an effort to promote development of improved methods, to enhance the training of clinicians and professionals, and to advocate proper use of analytic tools in health policy. Collaborations with clinical investigators ensure that these activities will be clinically relevant and in pace with new medical advances. Questions of the kind described in this issue of Risk in Perspective lie at the heart of the new research venture.

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Further Readings

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DC Hadorn. "Setting health care priorities in Oregon: cost-effectiveness meets the rule of rescue," *JAMA*, vol. 265, 1991, pp. 2218-2225.

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