Trust and Informed Consent to Rationing

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THE LAW OF INFORMED CONSENT IS IMPORTANT, BUT it has distinct limitations for framing the crucial questions as we encounter an increasing gap between what medical science and technology make theoretically possible and the willingness of our society to finance it. The dialogue between Hall (1993) and Appelbaum (1993) raises fascinating questions, but it is distant from the realities of everyday practice and clinical decision making.

Hall (1993) cites me as a proponent of prior consent on health care rationing, but the implications of my discussion are somewhat different than he implies. My proposal was a response to a tendency in marketing efforts to engage in expansive rhetoric, promising comprehensive benefits and health maintenance without revealing the utilization control mechanisms likely to be used. As I wrote:

When such plans are marketed, they usually promise a comprehensive benefit package, although there is often in reality a reluctance to provide some of the benefits advertised. Enrollment in an HMO [health maintenance organization] is really an agreement between the enrollee and the plan to accept a situation of "constructive rationing," although such plans are not typically described to consumers in this way. For a lower premium, more comprehensive benefits, or both, the consumer

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218 David Mechanic

implicitly agrees to accept the plan's judgment as to what services are necessary. The nature of this agreement is not made explicit. . . .

In individual instances, deception and falsification are evident in some marketing efforts, but to dwell on these abuses misses the larger point. Even in reputable plans, the scope of promised services is more than the plan hopes to provide, and a variety of barriers are put in the way of the consumer who attempts to obtain them. For example, enrollees are told that HMOs are organized to provide care as early as possible in sickness episodes. What they are not told is that HMOs eliminate economic barriers to access but replace these with a variety of bureaucratic impediments and limitations on the resources provided that keep enrollees from using too many services. (Mechanic 1986, 214-15)

It is not unrealistic to expect competing health care plans to accurately describe their operating procedures, expectations of patients, and the processes patients must follow in seeking medical care of particular types; included would be identification of the personnel who will make appointments and triage the patient and an outline of how they function. These descriptions could be made more concrete were they supplemented by information on telephone waiting time, average number of days for a primary care appointment, average physician/nurse visits, and other relevant information. Some plans provide such information now. Health plans can make arrangements for patients to visit treatment settings to get a first-hand impression of the site of their future care. Some plans encourage this, and enrollees who make such visits are less likely to disenroll in the future (Mechanic, Weiss, and Cleary 1983). Presumably. the report cards proposed in the Clinton plan are intended to meet some of these informational needs in allowing clients to make informed choices among plans.

A great deal hinges on what is intended within the concept of the plan's judgment as to what services are necessary. Hall, I believe, relieves plans too readily from an obligation subsequently to inform patients about beneficial treatments being withheld, only making exceptions for decisions that are "so dramatic and high-stake, such as pulling the plug on life support or declining a life saving operation for a terminally ill patient" (Hall 1993, 664). Appelbaum, in contrast, seems to reject the utility and meaningfulness of the concept of medical necessity, and it is difficult to glean from his description what revelations are and are not necessary. The case he cites of Ms. Wickline, whose leg required amputation owing to postoperative complications following hospital discharge,

is not helpful because the surgeon believed that additional hospital days "were medically necessary." To the extent that the surgeon had a reasonable basis for this view, he had an obligation to inform the patient and in addition, I would argue, to advocate vigorously for the patient with the insurer.

The underlying difficulty is the uncertainty of medicine, the extraordinary range of practice variations, and the frequent absence of an objective standard to sustain a specific practice decision. Under such circumstances errors occur in providing both "too much" and "too little" care, and each type of error may be exaggerated depending on whether fee-for-service or capitation-like incentives are operative. It is important that patients understand in a general way the incentives that are likely to affect their physicians' behavior under uncertainty, but it would be ludicrous for physicians to reveal all of the uncertainties and possible options that affect the decision-making calculus, even if they could articulate and explain them. In contrast, physicians have an affirmative obligation to protect their patients from harm and to inform them if, in their judgment, the constraints imposed by a health care plan are injurious to their health.

As Arrow pointed out decades ago, "Medical care belongs to the category of commodities for which the product and the activity of production are identical. In all such cases, the customer cannot test the product before consuming it, and there is an element of trust in the relation" (Arrow 1963, 949). The issue remains, and if, in selecting their physicians, patients are basically purchasing trust, then information about specific clinical judgments is less important than understanding how organizational arrangements and contractual relationships between physicians and plans bear on the issue of trust.

Despite the rapid growth of HMOs and other forms of managed care, many patients do not understand either managed care arrangements or the implicit contracts that define their relations with such programs (Mechanic, Ettel, and Davis 1990). Most fundamental is the extent to which patients understand that the role of the physician as the patient's agent and advocate shifts in subtle ways under managed care to one that more consciously balances actions on behalf of the patient against budgetary considerations (Mechanic 1986). I suspect that most physicians under managed care continue to view themselves primarily as patients' agents and do not readily compromise their professional judgments of appropriateness of care, but at the margins, or in situations of uncertainty, the operating incentives make a difference. This is particularly the case when

220 David Mechanic

administrative arrangements in an HMO or utilization management program place physicians under unusually strong constraints. Such constraints include putting primary care physicians at personal financial risk for exceeding utilization targets, a practice followed by 23 percent of forprofit plans surveyed in 1987 (Hillman 1987). Such incentives are associated with fewer outpatient visits per enrollee (Hillman, Pauly, and Kerstein 1989), suggesting that the constraints deter patient utilization.

The idea that one's personal physician balances interventions against program cost or other considerations makes many patients uncomfortable. In a recent study of a university employment group, with a majority of well-educated and sophisticated consumers, more than two-thirds of those choosing both an HMO and a traditional plan rated as very important "feeling that your doctor is only concerned about your health and not about limiting the plan's cost" (Mechanic, Ettel, and Davis 1990). Only two other areas were rated more important: getting an appointment with your doctor quickly when you want one and feeling that your doctor's concern about your health is his or her primary commitment. The vast majority of new HMO enrollees believed that "in this plan the doctor is only concerned about my health and not limiting the plan's cost," a perception clearly in error. Some analysts have little concern about such misperceptions, assuming that enrollees will learn about rationing processes quickly, but the potential implications of such rationing are not likely to be salient until serious illness strikes and expensive diagnostic treatment and rehabilitative technologies are at issue.

In short, there is need for more explicit contractual understanding up front: potential enrollees should be told about the degree of constraint on their future medical care. Specifically, the types of financial arrangements used to influence physicians in the allocation of care should be clarified. To the extent that HMOs routinely substitute less expensive personnel for physicians (nurses, social workers, etc.), or use less expensive forms of therapy (group versus individual psychotherapy), or seek to substitute community services for inpatient care, prior disclosure should be required. Individuals selecting among health care plans have more opportunity to make informed choices when such information is available, and a disclosure requirement, which may discourage enrollment, is a deterrent to the most extreme of such practices.

The preceding discussion refers to the very large range of practice variations where physicians making decisions truly believe that less expensive substitutes, or withholding care, is not detrimental to patients' health.

Comparable disclosure requirements should apply to fee-for-service (FFS) practice, particularly in the area of financial relations with facilities to which physicians refer. FFS incentives create tendencies for too much care, some of which may expose patients to unnecessary risk and iatrogenic injury, but this is a financial relation and pattern of risk that patients understand better than managed care.

Prior disclosure is of limited efficacy, however, because enrollees are often inattentive to remote risks, and the information may seem of little relevance when first presented. Physicians thus continue to have a duty as the patient's agent, whatever the financial and organizational arrangements, to protect the patient from actions and decisions that are detrimental to their welfare. When the physician believes that the patient will be harmed by an organizational decision, and not simply denied amenities, the doctor has an obligation to advocate for the patient and, if advocacy fails, to inform the patient.

Physicians may disagree on when a patient will suffer harm, and such variations will continue to be common in practice despite the introduction of practice guidelines. In the absence of convincing outcome data, the range of appropriateness has to remain fairly large and allow considerable physician discretion. When physicians within the same plan disagree about whether withholding particular services is injurious, and the plan denies care against the treating physician's advice, the physician should so inform the patient and assist the patient in pursuing whatever appeal process is available. Physicians who find themselves in a continuing adversarial role with their plans should probably seek alternative practice opportunities.

Managed care is a rapidly growing sector, and abuses will undoubtedly occur, not unlike abuses in FFS practice. Despite much rhetoric and anecdote, there is little evidence overall that care is being unreasonably managed or that the dire consequences predicted by critics are likely to occur. In fact, so little care is presently denied that skeptics question whether managed care is cost effective (U.S General Accounting Office 1993). Moreover, well-administered managed care expands treatment possibilities and allows flexibility in choosing among therapeutic options. Nevertheless, it is prudent to establish a structure that minimizes potential problems.

Informing potential enrollees is only one of several interrelated measures that will contribute to containing potential abuse. Combined with opportunities for enrollees to select from alternative plans, to be able to

222 David Mechanic

shift easily to other plans, and to benefit from the availability of standardized and increasingly sophisticated performance information, a higher standard of informed consent on the philosophy and format of clinical decision making can make a meaningful contribution. In the absence of evidence that the care provided was negligent, the presumption should support physicians who implicitly ration within a contractual framework.

In the short run, there is sufficient waste in the medical care process to assume that much care could be withheld without injuring, and perhaps even benefiting, patients. In the future, however, there will be instances where very expensive and useful technologies or interventions are rationed solely because of their cost. In such instances involving very large expenditures, public discussion and an explicit decision-making process is desirable, and noncoverage of these technologies should be stated explicitly in the contract.

Patients enrolled in managed care systems who are appropriately informed about the contract also assume obligations. Patients should be discouraged from insisting on services covered by the benefit package but not medically necessary. Although such demands inevitably will occur, an honest portrayal of the contract up front should help constrain them. Overly exacting patients are not particularly common, but they have undue influence on the physician's self-respect and morale, and fundamentally challenge the role of physicians as professionals exercising their best clinical judgment (Freidson 1975).

Tougher health care decision making is inevitable whether we like it or not. As we evolve new frameworks for care, dissatisfactions, complaints, and litigation are inevitable. Key to the transition is whether patients feel that physicians are their agents and act in their interests. Such perceptions can be facilitated by truthfulness, by conveying a clear understanding of contractual relations, and by accessible and user-friendly channels for making complaints and having them adjudicated. It depends also on the integrity of physicians in serving as patient advocates when they believe that organizational decisions are injurious to their patients.

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