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## **53. Ethical Issues in Health Care Systems Reform: The Provision of Adequate Health Care**

### **Introduction**

Resolution 135 (1-92), which was introduced by the Hospital Medical Staff Section and referred to the Board of Trustees, asked the Council on Ethical and Judicial Affairs to study the impact of cost-containment health care reform proposals and various rationing concepts on medical decision making and the existing medical ethics standards. The Council responds to the resolution with this report.

It is the policy of the American Medical Association that every citizen should have access to adequate health care: "The patient has a basic right to have available adequate health care."<sup>1</sup> In this report, the Council discusses the ethical foundations of society's obligation to ensure that none of its members is denied access to adequate health care because of an inability to pay for it. This obligation rests primarily on the belief that a just society affords its members reasonable protection from illness and a fair opportunity to enjoy life.<sup>2,3</sup>

The Council also discusses in this report the definition of "adequate health care" because it is an essential step in guaranteeing meaningful universal access. The Council believes that the definition should follow consistent ethical principles and take the form of a basic package of benefits that is available to everyone. Because financial constraints dictate that not all potentially beneficial health care services can be realistically included in a basic package, some prioritization of health care services must take place. This report will offer ethical criteria to guide the prioritization of health care services, but will not actually prioritize services. A proposed benefits package has been developed in Council on Medical Service Report A (A-93), AMA Required Benefits Package,<sup>4</sup> and it is entirely consistent with the principles developed in this report.

This report is about society's obligation to provide access to care. Physicians have an ethical obligation to provide care to those in need which is discussed in prior Council reports and opinions. In addition, individuals have an obligation to be responsible for their own health and health care. No society can guarantee good health, and much more than guaranteed access to adequate health care is necessary to materially improve the health of the nation.

### **Background**

Despite the high quality of health care available in the United States to many Americans, not all Americans have access to adequate health care, and there has been no formal commitment to guarantee universal access. Medicaid, the federal program created in 1965 to provide insurance benefits to persons living in poverty, has been increasingly unable to meet this goal. In 1973, 63% of people with incomes falling below the poverty line were eligible for Medicaid.<sup>5</sup> Currently, only 40% of those below the poverty line are eligible,<sup>6</sup> leaving the majority of the poor uninsured.

In addition to inadequate access to health care, the United States, like all other countries, faces the well-documented problem of costs. In 1991, for example, the U.S. spent a total of \$738 billion on health care or nearly 14% of the GNP.<sup>7</sup> Whatever the appropriate level of spending, to the extent the amount includes unnecessary costs, fewer resources are available for the poor and uninsured.

## **Society's Obligation**

The policy of the American Medical Association supports society's obligation to provide enough resources so that no patient is deprived of necessary care because of an inability to pay for that care. (Policy 140.975, 1993 AMA Policy Compendium) This obligation to provide access to an adequate level of health care stems from two sources. The first is the duty of society to protect its members against such general threats as foreign military aggression, crime, fire, and disease. This duty is derived from the view of society as the product of a social contract between citizens, who abide by the mutually agreed-upon rules or laws of society in order to gain the benefits of collective protection and economic and social cooperation.<sup>2</sup>

Ordinarily, the duty of collective protection derived from the social contract applies only to threats to the public at large, rather than threats to particular individuals. Thus, the duty of collective protection clearly imposes an obligation to promote public health through such measures as the provision of a safe water supply, clear air, building codes to ensure sanitary living conditions, and inspection of the food supply. However, the duty of collective protection also requires that at least some of the health care needs of individuals be met. Individuals with highly contagious diseases, for example, pose a threat to the health of other members of their community, and society invests in physician training, hospital construction, and medical research, all of which extend beyond the traditional conception of public health.

Society's obligation to provide access to an adequate level of health care is also grounded in the moral concept of fair opportunity. The principle of fair opportunity holds that each member of society should have adequate opportunity to cultivate talents and develop skills, formulate life goals, and pursue those goals without unjust interference from others. Fair opportunity creates two obligations for society to fulfill. The first is to provide each member with a reasonable opportunity to achieve well-being by ensuring that each has adequate amounts of those primary goods which all individuals need to survive and flourish. These primary goods include such necessities as food, shelter, clothing, education and fair opportunity for good health.

The second obligation derived from the principle of fair opportunity is to ensure that the opportunities available to individuals are not unfairly affected by traits and circumstances over which the individual has no control and hence cannot be said to deserve. Examples of such undeserved traits might include race, gender, or height. Making opportunities available to some and not to others on the basis of these characteristics or other undeserved traits would clearly be unjust.

The contribution of health care to individuals' overall health status varies significantly among individuals, making it difficult to specify an amount of health care that each person should be entitled to in order to provide fair opportunity. Health care's role in the provision of fair opportunity is different from other primary goods, such as food, simply because different people will need different amounts of health care in order to function. However, while society has no obligation to ensure equal health care for all individuals, there is an obligation to ensure access to a decent level of health care for everyone.

## **Adequate Health Care**

Society's obligation to provide collective protection and fair opportunity does not entail a commitment to provide all possible health care to everyone. When providing other social goods, like food, housing and education, society's commitment is to satisfy adequate rather than maximal standards. For example, while public housing should be safe and well maintained, it need not be extravagant. Similarly, society does not have an obligation to provide every potentially beneficial treatment to be fair, but a firm standard should be created to ensure that no individual has inadequate health care. Accordingly, the relevant ethical debate

about how to fairly distribute health care rests on the question of how to ensure adequate health care for all.

1. **A Theory of Adequacy.** Although fairness requires that society define "adequacy" in health care, the task is made particularly difficult by the subjective and expansive nature of health care needs. In 1947, the World Health Organization defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."<sup>8</sup> If the adequacy of health care benefits was judged by its ability to bring individuals closer to the WHO's concept of health, then it is difficult to see how any limit could be placed on health care benefits. In 1990, the bipartisan Pepper Commission defined a functional minimum benefits package to include "hospital care, surgical care and other inpatient physician services, physician office visits, diagnostic tests, and limited mental health services (45 inpatient days and 25 outpatient visits), and preventive services including prenatal care, well-child care, mammograms, Pap smears, colorectal and prostate screening, procedures and other preventive services that evidence shows are effective relative to cost."<sup>9</sup> This example gives some shape to the idea of an adequate level, but it also risks being too broad. Lists of general types of services do not differentiate between essential and inessential specific services.<sup>3</sup> For example, the Pepper Commission's list suggests that all hospital or surgical care should be covered, no matter how elective are the justifications for the care. In addition, the list leaves open the question of what amount of effectiveness is worth its cost.<sup>9</sup>

The Oregon Medicaid experiment also illustrates the difficulty in defining an adequate level of health care. After prioritizing different health services according to their comparative benefits,<sup>10</sup> the legislature drew a line between covered and uncovered services based on the amount of money it was willing to allocate for the services. By using a financial cutoff to define the basic benefits package, Oregon allowed its package to be limited ultimately by an arbitrary economic cap rather than ethical judgments about adequate health care. Under the Oregon plan, the definition of adequate health care will vary from year to year depending upon the state of the economy rather than on the health needs of its citizens.

Many commentators have argued that the failure of policymakers to appropriately define adequate health care reflects the failure to develop a theory of adequacy that is based on ethical principles. Such a theory would provide a "gold standard"<sup>7</sup> for determining the content of a health benefits package and would safeguard against an unfair allocation of medical services.

Despite the importance of defining a theory of adequacy, it seems unlikely that an absolute or universal definition will ever be agreed upon. First, there is inherent variation in health care needs and preferences. Individuals differ on the aspects of health that are important to them and on their toleration of risk. As a result, people differ widely in their preferences among the medical treatments for a particular disease or among the treatments for different diseases. Developing a universal theory is also hampered by variations in preferences between medical care and non-medical priorities such as education, housing, and other valued goods.

Health care preferences vary not only at the individual level but also at the community or cultural level. Diverse, culture-specific standards for what is adequate make it difficult to expect every populace to adopt the same values, expectations and priorities. Preferences may differ not only among ethnic or socioeconomic groups within the United States but also from one country to another. Americans might not be satisfied with the health care Canadians receive. Although some critics have suggested that Americans have unrealistic expectations about health care, a successful policy for a decent minimum must take into account the culture of the population for which it is intended.

Another barrier to the formulation of an absolute theory of adequacy is the lack of a close correlation between health and health care. While government-defined, dietary requirements generally reflect good nutrition, the amount of health care needed for adequate health can vary substantially. For patients with a

strep throat, simple and inexpensive antibiotic treatment will restore good health. For other patients, even the most comprehensive and advanced medical care cannot always ensure an adequate level of health. In many cases, access to health care must be combined with other social goods, like food and housing, to ensure adequate health.!! In other cases, even the most minimal level of health cannot be achieved no matter how much health care and other services are provided.

Even if a theory of adequacy could be developed, it would be very difficult to implement. Because of the wide variations in medical needs from person to person, general principles would not take into account the particular conditions of individual patients. A treatment that might be reasonable and necessary to provide to one individual - and hence would seem to be included in a definition of an adequate level of health care - might not be appropriate for others. For instance, while coronary bypass surgery would generally be considered part of an adequate level of health care, it might not be considered basic care in patients with multiple, serious medical problems. If a formula or a detailed list of benefits were developed to account for individual variation, it would become hopelessly complex. Moreover, changes in medical technology and knowledge would render it obsolete very quickly.

2. **Relevant Ethical Principles.** While it may not be possible to define an absolute theory of adequate health care, ethical principles can still guide the determination of adequate health care benefits. Society's resources should be allocated efficiently so that they have maximum impact on preserving and restoring the health of patients. In the evaluation of particular procedures or treatments, several factors are relevant to ensuring the efficient use of health care resources. These include the duration of benefit, the degree of benefit, the likelihood of benefit, the number of people who will benefit, and the cost.

a. **Duration of benefit** is relatively straightforward. Treatments that eliminate an illness or a risk of illness permanently are more basic than treatments that can have only a temporary effect. Similarly, treatments that must be repeated are less basic than treatments that require only a single administration. In some cases, the patient will have other medical problems that limit the duration of benefit. For example, replacement of a heart valve will have less of an impact on life expectancy for patients with a terminal disease. It is therefore important to consider all factors that affect a treatment's duration of benefit.

b. **Degree of benefit** refers to the difference in outcome when comparing treatment and no treatment. For example, the maximum degree of benefit occurs when a treatment prevents the development of a condition that would be fatal without the treatment. Accordingly, preventive measures have the potential for a greater degree of benefit than do treatments after the occurrence of disease. By comparing the outcome with treatment to the outcome without treatment, degree of benefit also takes into account the risks of complications from the treatment.

In some cases, the degree of benefit will be lessened because the patient has other medical problems. For such cases, the care may no longer be basic. However, it is important to distinguish between the benefit from the treatment and the patient's underlying degree of function. Relief of an esophageal obstruction confers the same benefit on infants with Down's syndrome as on otherwise healthy infants. On the other hand, chemotherapy confers a smaller benefit for metastatic breast cancer than for localized breast cancer.

c. **Likelihood of benefit** is relevant in a number of ways. For diagnostic tests, like mammography or colonoscopy, the desirability depends on the likelihood that an abnormal finding will result. Consequently, some tests may be basic for only certain segments of the population. For treatments, the desirability depends upon the treatment's efficacy. Accordingly, if empirical data have not demonstrated that a treatment is effective, then there is insufficient

justification for its use. Likelihood of benefit may depend upon the patient's overall medical condition; all factors that affect likelihood of benefit must therefore be taken into account.

**d. Number of people benefiting** can be measured in at least two ways. First, a treatment can benefit the patient who receives it and others who come into contact with the patient. Vaccinations and antibiotics for infectious diseases are examples of such treatments. Second, a treatment may respond to a medical condition that is relatively common. Its inclusion in the basic package would therefore benefit more people than the inclusion of a treatment for a rare disease. While the first way to view number of people benefiting is ethically relevant, the second is not. Whether a person receives treatment for a disease should not be affected by how common the disease is. It is true, of course, that treatment for a rare disease is often very expensive. Consequently, for a fixed amount of money, it is possible to treat fewer patients with the rarer disease. While the higher cost of treatment for a rare disease may be ethically relevant, the fact alone that it is uncommon is not ethically relevant.

**e. Cost** alone is not a reason for including or excluding a treatment, but cost relative to effectiveness or benefit is highly relevant. In some cases, it is simple to apply cost considerations. For example, if one treatment achieves the same goal as another treatment, but at lower cost, then it is clearly preferable.<sup>2(p.232-233)</sup> Treatments that are less effective but less costly, and treatments that are more costly but more effective may also be more desirable, but it depends upon how much benefit is lost or gained from the cost savings or expenditure.

**3. Applying the Ethical Principles.** There is no simple formula for applying the five ethical values. Some treatments will satisfy all of these values in a substantial way and therefore should be included as part of an adequate level of health care. For example, the polio vaccine confers life- time protection against a serious disease that threatens all individuals, and it does so for only \$18.35 per person.<sup>12</sup> In other cases, it will be enough if a treatment satisfies a few of the ethical values in a substantial way. For example, appendectomies can permanently eliminate a serious threat to a patient's life. While it is not necessary to serve all of the values, sometimes the failure to serve one of the values will preclude inclusion of the treatment in the package of adequate health care benefits. For example, if efficacy has not been demonstrated, or there is no significant benefit, or an alternative treatment is available with the same benefits at lower cost, then a treatment should not be included.

**4. Fair Process.** In the absence of a complete theory or simple formula for determining the adequate level of health care, it is essential that the ethical principles be complemented with a fair process to determine the exact content of adequate health care. As Beauchamp and Childress have observed, "[w]here it is difficult to resolve disputes about substantive standards, such as an adequate level of health care to satisfy the minimum required, it is usually necessary to revert to procedural rules."<sup>2(p. 289-290)</sup> A just outcome can be achieved by either a just theory or a just process for implementing the relevant ethical values. As long as the process is constructed to be fair, the resulting definition of adequate health care would be just. The way the procedural rules are created and implemented, however, is of utmost importance. As the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research concludes, "It is reasonable for a society to turn to fair, democratic political procedures to make a choice among just alternatives. Given the great imprecision of the notion of adequate health care, however, it is especially important that the procedures used to define that level be - and be perceived to be - fair."<sup>13(p.42)</sup>

## Ethical Considerations in a Fair Process

To ensure fairness, the process for determining the level of adequate health care should include the following elements or considerations:

1. **Democratic decision making.** A democratic process should be used to determine the content of an adequate level of health care. Because of the strong subjective element inherent in choosing what health care services are essential, it is critical that all citizens have equal input into the process. Thus, while a commission or task force of medical experts might draft a formal proposal, it should be subject to approval through legislative vote. If society's members are to live with the definition of adequate minimum, the process which creates the benefits package should be accountable to the public.

Public input is critical not only at the approval stage but also in the development stage. As the proposed benefits package is being developed, broad public input should be solicited. Including the value judgments of the people most affected by the allocation choices ensures that the process and its results will more likely be fair. A system that uses the choices of "average"<sup>9</sup> or representative<sup>14</sup> patients to define the content of a minimum package might be considered.

A democratic process will ensure visibility of the process to define the adequate minimum of health care. Currently, allocation decisions are sometimes made by physicians or hospitals without patient involvement or even patient awareness. Though these decisions are usually made with patients' best interests in mind, the lack of broader participation may result in some arbitrary or unfair decisions. An open, democratic process will help promote fairness in allocation decisions.

2. **Role of physicians in resource allocation decisions.** On a societal level, physicians have a great deal to offer those who are defining the adequate level of health care. For the public to express its preferences, it must have a solid understanding of the benefits, risks and costs of the different kinds of health care that can be funded. Physicians have a responsibility to participate and to contribute their professional expertise in order to safeguard the interests of patients in any decisions made at the societal level regarding the allocation or rationing of health resources.

Because physicians decide when care will be provided to specific patients, they also have a potential role in deciding whether a particular patient's care falls within the adequate level of health care, once the level has been defined. Most ethicists have rejected a role for the physician as bedside rationer of health care.<sup>15,16</sup> Bedside rationing can result in arbitrary decision making in which a patient's care depends on the values of the physician providing care rather than on generally accepted values. However, it would not be possible to eliminate all physician discretion in resource allocation decisions. While society can develop a definition of adequate health care, it can only provide general guidelines to physicians. Society cannot develop precise formulas that give clear answers for all patients in all circumstances. Accordingly, physician discretion can be limited but should not be eliminated.

To prevent inappropriate allocation decisions by physicians, safeguards need to be erected. Physicians' historic ethical duty to be their patients' advocate should be reinforced and protected. Financial incentives to limit care should be examined and limited. Patient care should be monitored by physicians to determine whether variations in care occur that cannot be justified on medical grounds.

3. **Ensuring the adequate level.** The obligation to provide an adequate level of care has two important aspects. The principles of collective protection and fair opportunity apply to all members of society, especially those least able to protect and provide for themselves. Thus, in addition to designing an adequate package of health care benefits that all individuals will receive, the health care system must

ensure that the benefits are not eroded over time for those who are unemployed, indigent or otherwise disadvantaged. When Medicaid was conceived, it was designed to cover all of those whose incomes were below the poverty line. Currently, only 40% of the poor are covered by Medicaid. Similarly, in the past ten years, the number of homeless has risen from about 1 to 3 million,<sup>17</sup> despite the existence of a federal housing program to provide shelter for those in need.

Historically, the needs of the indigent have most nearly been met when their benefits are linked in some way to the benefits of the wealthier segments of society for example, the elderly poor generally receive adequate health care benefits because the Medicare program covers all Americans age 65 or older. When the interests of the poor are provided for separately from those of the better off, the gap between the poor and non-poor generally widens over time. In difficult economic times when budgets are limited, legislatures often do not appropriate sufficient funds for programs that serve the poor.

An acceptable approach would be to provide the indigent the same level of health care benefits as included in a basic package of benefits received by employees of a state or the federal government, for example. While access to an adequate level of care should be the same for all individuals, people who can afford additional care should be free to purchase it.

**4. Preventing discrimination** Even if all segments of society receive the same benefits, there still may be inadequate attention to the needs of disadvantaged groups. In deciding whether a particular treatment is part of adequate health care, individuals will tend to place higher priority on treatments that meet their current or anticipated needs. Individuals with uncommon or stigmatizing conditions, as well as minorities with special health concerns, may have their needs disregarded and may lack sufficient political power to prevent unfairness. Indeed, treatment for psychiatric illness has traditionally been afforded less coverage than treatment for physical illness in health care plans, and patients with HIV-disease are finding that their coverage is less secure than coverage for patients with other terminal diseases that are expensive to treat. There also has been disturbing evidence of insufficient attention to the health concerns of African Americans,<sup>18</sup> women<sup>19</sup> and disabled individuals.<sup>20</sup> It is important therefore to pay special attention to the health care needs of disadvantaged populations (e.g., women, minorities, the disabled or the poor) who are at risk both for having greater health care needs and for having their needs overlooked.

Of particular concern are guidelines that appear to be objective or neutral but have the effect of disadvantaging certain groups. For example, a flat cap on the number of hospital days per year may disproportionately affect disabled individuals,<sup>21</sup> or a quality of well-being formula may disguise societal biases against certain kinds of disability.

When decisions are made to include or exclude a particular treatment from the basic package, the ethical values listed previously (duration, degree and likelihood of benefit, number benefiting and cost) will generally give clear guidance. However, in many situations, it will not be clear whether the treatment should be included in the basic package and difficult line-drawing decisions will have to be made.

To guard against inappropriate biases in the line-drawing, it is useful to consider Rawls' theory of justice. According to the theory, allocation decisions are most likely to be just when decision makers are operating behind a "veil of ignorance." Behind the veil of ignorance, decision makers determining the rules governing allocation would be prevented from knowing their own particular situation in society, so that their decisions would be made objectively rather than from their own unavoidably subjective perspective. Applying this theory to health care allocation, if decision makers do not know what their medical needs will be and have to assume that they could be poor or rich, healthy or disabled, then they will choose basic health care benefits that would be fairest to everyone. In the real world, the fairness of allocation decisions would be measured by whether they are the kinds of decisions that would result if

decision-makers operated behind a veil of ignorance.

While it is not possible to create a veil of ignorance, it is possible to approximate that construct by using an equal consideration mechanism for decisions when the decisions are not clearly governed by the relevant ethical values. Under equal consideration, for treatments that are neither clearly basic nor clearly discretionary, each treatment would be given an equal chance to be included in the basic package. Since there are no objective grounds for choosing between treatments that are of approximately equal efficacy (as determined by the five ethical criteria discussed earlier), equal consideration is the fairest way to determine which of these treatments are included in the adequate level of health care.

**5. Ensuring broad acceptance.** A process that is designed to be fair may nevertheless lead to unfair outcomes. It is therefore important to monitor public satisfaction over time to ensure continued and broad public acceptance.

It is unlikely that a defined level of health care would be considered adequate if many people opted to supplement it. Conversely, if people generally are content with their basic package of benefits, as is the case with people who have employer-provided insurance currently, then it suggests that the package is adequate.

## **Reform**

There are several proposed reforms for the health care system that include the means to provide an adequate level of health care to all Americans. It would be ethical to use a market-based system with vouchers for the poor as well as managed competition or a single-payer system. This report does not endorse one method over another but raises the ethical issues that are relevant in evaluating different proposals. Inevitably, government will play a significant role in assuring that society meets its obligation to provide adequate health care to all.

Any reform to the health care system should make cost containment one of its important goals. Administrative waste, excessive liability costs, futile care, over utilization of expensive technology and diagnostic tests, and consumers who are shielded from the costs of their medical care all contribute to escalated spending and wasted dollars.<sup>22</sup> Justice requires that all parties take responsibility for eliminating unjustified expenditures and make all efforts to control health care costs.

## **Conclusion**

The assumption that no health care system can afford everything has always been true. Health care resources are finite and there are other societal needs, such as education and housing, which compete for dollars spent on health care. In a context of cost constraints not easily or quickly eliminated, it is essential that society fulfill its commitment to ensuring universal access to an adequate level of health care.

## **Recommendations**

The Council on Ethical and Judicial Affairs recommends that the following recommendations be adopted in lieu of Resolution 135 (1-92), introduced by the Hospital Medical Staff Section, and that the remainder of this report be filed. The following recommendations apply to a basic health benefits package.

1. Society has an obligation to make access to an adequate level of health care available to all of its members regardless of ability to pay.

2. In determining whether particular procedures or treatments should be included in the adequate level of health care; the following ethical principles should be considered: a) degree of benefit (the difference in outcome between treatment and no treatment), b) likelihood of benefit, c) duration of benefit, d) cost and e) number of people who will benefit (referring to the fact that a treatment may benefit the patient and others who come into contact with the patient, as with a vaccination or anti-microbial drug).

3. Ethical principles require that a fair process be used to determine the adequate level of health care. To ensure fairness, the process for determining the adequate level of health care should include the following considerations: a) democratic decision making with broad public input at both the developmental and final approval stages, b) monitoring for variations in care that cannot be explained on medical grounds with special attention to evidence of discriminatory impact on historically disadvantaged groups, and c) adjustment of the adequate level over time to ensure continued and broad public acceptance. Because of the risk that inappropriate biases will influence the content of the basic benefits package, it may be desirable to avoid rigid or precise formulas to define the specific components of the basic benefits package. After applying the five ethical values in Recommendation 2, it will be possible to designate some kinds of care as either clearly basic or clearly discretionary. However, for care that is not clearly basic or discretionary, seemingly objective formulas may result in choices that are inappropriately biased. For that care, therefore, it may be desirable to give equal consideration to the different kinds of care when deciding which will be included in the basic benefits package.

4. The mechanism for providing an adequate level of health care should ensure that the health care benefits for the poor and disadvantaged will not be eroded over time.

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