



Ethical Issues in Managed Care: Guidelines for Clinicians and Recommendations to Accrediting Organizations

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by Joan D. Biblo, Myra J. Christopher, Linda Johnson, and Robert Lyman Potter

Executive Summary

Much like American society as a whole, the bioethics community awakened slowly to the realization that the delivery of healthcare has been profoundly altered by the growth of managed care. At the time this project was conceived, it appeared that the Clinton healthcare reform proposals would greatly accelerate the trend toward managed care. For the ethics community, this meant that it was time and probably past time, to review the ethical assumptions applicable to traditional fee-for-service medicine and those in managed care.

In the traditional fee-for-service system, ethics has been predominantly driven by the principle of autonomy and has been the responsibility of providers—physicians and hospitals. Its focus has been on codes of ethical behavior and patients' rights statements. This model of ethics has supported a healthcare delivery system that focused on the individual patient, protected physician autonomy, promoted treatment that offered potential benefit or prolonged life, and assumed unlimited resources. Clearly, there have been ethical problems associated with a fee-for-service model including overutilization and rationing on the basis of financial means; however, fee-for-service issues will not be the focus of this document. Rather, the task force was convened to attempt to meet the needs of an expanding managed care industry which is ready for formal consideration of its ethical framework.

As healthcare costs have risen excessively and pressures have increased to limit healthcare expenditures, managed care has become a viable alternative to the fee-for-service model. The managed care alternative uses capitation as one mechanism to limit costs, introduces the plan as an agent in decision making, and shifts the focus from being exclusively on the individual patient to give due regard to the well-being of the membership.

A basic managed care concept is that managed care providers help keep treatment costs down, for the benefit of each patient and of the membership as a whole. Hoped-for results are not only that the individual will receive appropriate quality care but also that the entire membership of the managed care plan will pay lower premiums and can be offered additional benefits (such as preventive care, often not covered by traditional health insurance). In this sense, managed care is not exclusively focused on the treatment needs of individual patients but is also attentive to the needs of the membership as a group. At the same time, as a result of the search for lower costs, individual patients in a managed care plan can be saved from unnecessary tests and treatments, which is a risk inherent in the traditional fee-for-service system.

Managed care plans have a responsibility to the entire membership to conserve resources in order to provide affordable care to their members. Living within limitations necessarily means allocating resources. Imposing limits and allocating resources necessarily leads to conflict. The resolution of these conflicts requires equitably balancing the interests of all who have claims to limited resources. Elucidating basic principles to help balance such competing interests rationally and fairly is one function of ethics and is the task of this project.

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The project developed in several phases through which the opinions and expertise of different groups were gathered and incorporated. Initially, focus groups of consumers, physicians and nurses in managed care organizations were held to identify basic concerns and issues from which ethical issues then were derived. In the next phase, this information was shared with a steering committee of nationally recognized health care opinion leaders, many from managed care. In a day-long process, steering committee members prioritized the ethical issues that had been identified.

The steering committee recommendation — to develop ethical guidelines for managed care organizations, particularly related to the process of resource allocation — became the primary mission of the task force, the third phase of the project. The task force consisted of twenty-four members including local providers and managers of health care, ethicists from university settings, and staff from the Center for Practical Bioethics, then known simply as Midwest Bioethics Center. Over the next six months, this group became the testing ground, developer, and refiner of all of the ideas contained in this document. Prior to each meeting, task force members received a revised draft of the work completed to that point and articles which provided information relevant to the project.

Task force members were remarkably willing to meet the time and energy demands required. Throughout the process they were outspoken and open in sharing their individual experiences and perspectives. As the group developed, it became clear which “burning issues” would elicit responses from members of the group. There were the “member responsibility” advocates; those who recoiled from “rationing”; the “member input” and “member autonomy” zealots, and those who kept trying to bring us back to the practical, real world of probabilities and possibilities.

With all this diversity and honest exchange of opinions, the task force still managed to adhere to a consensus model of decision making. If the group truly could not reach general agreement, the idea was initially put into a “parking lot” or list of ideas which the group would have to revisit at a later time. Members who had opinions on issues that remained unreconciled were invited to prepare a footnote to be added to the document. The group developed and maintained a mutually respectful commitment to the dialogue and process, despite differences.

After each meeting a work group of three to four staff members from the Center took the input from the task force and rewrote the document. This group, too, had frequent points of disagreement, not only about what each of us heard the task force members saying, but on whether or not consensus had been reached and, thus, whether we could revise the document. The writing group resisted the temptation to shape the document to match any of their own opinions. In addition, there were frequent conference calls to members of the steering committee who received regular updates of the draft document. Their expertise, credibility, and knowledge were a helpful balance.

The document consists of the following pieces:

- A summary of the **Ethical Foundations** underlying much of health care decision making, with an emphasis on justice and a virtue perspective, tempered by considerations of the good of the membership as a whole.
- **Shared Assumptions** that the group agreed were basic to their understanding of health care.
- An expanded list of **Member Rights** and a brief list of **Member Responsibilities**, and expanded **Plan and Provider Responsibilities**.
- **Guidelines to Ethically Allocate Resources and Resolve Conflicts**.
- **Future Issues**, including **Rationing** and **Social Responsibility**.

In the last phase of the project, the steering committee was asked to review the document and to recommend accreditation standards for ethics to national accrediting organizations.

Through the intense discussions of the task force, an understanding was reached that two biomedical principles, respect for patient autonomy and acting in the best interest of the individual patient, have dominated the clinical ethics conversation. With the growth of managed care, concerns about justice, or how to fairly distribute medical services to meet the needs of a designated patient population, have entered the ethics conversation. Recognizing and accommodating this additional ethical concept while preserving respect for the individual and acting in the best interest of the individual continues to challenge both providers and patients.

Nothing in this document is meant to imply that managed care plans have not been concerned with ethical behavior. Rather, with input from ethicists and others, the providers and managers on the task force tried to articulate the ethical issues, clarify ethical principles that apply, and determine how managed care plans can integrate formalized ethical approaches to resolve inevitable tensions.

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The change to managed care might be less threatening if the decisions of managed care plans are perceived to be rational, fair, and respectful of provider and patient needs. This guideline document is an attempt to assist plan managers and providers to ground decisions in recognized ethical principles and maintain an environment in which ethical principles are explicit and integrated into day-to-day operations. The members of the task force sincerely believe that organizational ethics can be the bedrock of quality, compassionate care. Even though cost reduction has become a standard of success, task force members believe that in the long run, managed care organizations without a commitment to ethics will not survive in the marketplace.

Project Mission

The mission of the managed care project was to improve the quality of health care in the United States by *supporting* a culture of ethical sensitivity and behavior in managed care organizations.

Project Objectives

The objectives of the project:

- 1) to create a guideline document intended to assist plan managers and providers as they work through ethical issues;
- 2) to recommend to the NCQA board of directors standards intended to promote the rights of members and enhance ethical organizational practices.

Project Description

The bioethics movement originated to bring new perspectives into health care decision making, an area which had been exclusively the domain of physicians. The movement has been predominantly hospital oriented, and little work has been done in managed care. Over the last decade, the Center for Practical Bioethics has followed the traditional patterns. However, the Center recognizes that with the tremendous growth of managed care, it is increasingly important for the ethics community to give attention to managed care and to respond to its particular needs.

Review of the literature and discussion with both local and national managed care leaders led the Center to believe that there was a need for formalizing ethics within managed care organizations. It appeared to Center staff that there was an opportunity to assist managed care organizations in dealing with their ethical issues. The Center also was aware that many hospitals had been motivated to create internal mechanisms for dealing with ethical issues because of the patients' rights and organizational ethics standards promulgated by the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO). The Center believed that the standards approach would encourage incorporating ethics into managed care as well.

The Center also believes that organizations which promote quality necessarily emphasize ethics. The National Committee for Quality Assurance (NCQA), the largest accrediting entity for managed care organizations in the United States, is genuinely interested in how ethics can improve quality and has recognized the importance of ethics by adopting a member rights standard and a grievance procedure standard. The Center wanted to investigate what more can be done through NCQA and how managed care plans can better support an internal culture which enhances ethical sensitivity and behavior in their organizations.

With support from the Prime Health Foundation, which focuses on managed care, the Center facilitated a year-and-a-half project to consider these issues. To legitimate the project, the Center adopted a grassroots approach involving consumers, managed care clinicians and administrators, and bioethics experts. To get beyond an exclusively local perspective, the Center brought together a steering committee of national health care leaders to set the project

agenda, review the work in process and, ultimately, to make recommendations about accreditation standards. The initial investigation was done in focus groups.

Focus Groups

Each of three managed care plans allowed access to a group of their physicians, a group of their nurses and a group of their consumers. The plans were Blue Cross and Blue Shield of Kansas City, Humana Health Plan, and Kaiser Foundation Health of Kansas City. Two consumer groups were combined into one; therefore, eight focus groups met. Both clinician and consumer participants were self-selected. The groups varied in size from five to thirteen members.

Each focus group began by brainstorming to learn what their general concerns about health care were. The discussion then moved to ten questions previously suggested by a review group made up of managed care providers and managers from the three participating organizations and Center staff. Specific issues probed included access to care, availability of information, changes experienced in the last five years, and practice guidelines. Participants were also asked about their general perceptions of managed care, adequate care and an "ideal" health care delivery system. All sessions were taped and transcribed.

General concerns raised in the initial discussion reflected much of the then current health care reform dialogue, and included

- Access to care
- Consumerism
- Increased bureaucracy
- Cost
- Resource allocation/rationing
- Choice of providers
- Education
- Discontinuity of relationships.

When asked about changes in health care over the last five years, participants did not respond positively. Physicians talked about increasing external pressures; nurses talked about taking care of sicker patients outside the hospital; and consumers talked about the need to be more assertive and informed in order to receive quality care.

Based on the literature, questions were formulated to find out if consumers believe they receive ad-

equate information to make informed decisions and if providers feel that the plans restrict them from giving information to their patients. Information for decision making did not seem to be a problem for participating consumers or providers. However, all participants felt that recently, patients have been required to change plans or providers more often than in the past and that the resulting disruptions in provider/patient relationships makes effective communication difficult.

Another question explored the meaning of "adequate care." Consumers and providers agreed on many points. All groups included universal access, affordability, and convenience when describing "adequate care." Consumers, however, emphasized non-clinical issues, such as relationships with providers, equality, and compassion. Clinicians emphasized the scope of services provided and continuum of care (meaning failure of communication between caregivers in different settings, such as hospital and physician). Physicians and nurses also included issues as diverse as consumer education, prevention, treatment of acute illness, and long-term care. Interestingly, in this part of the discussion, consumers did not mention "choice" as a necessary characteristic of adequate care; yet, both physicians and nurses did.

When asked to define managed care, all groups were essentially positive although there were some critical comments. According to these participants, managed care is a means of efficiently providing quality, cost effective, appropriate care to large numbers of people. There were many positive comments. For example, one physician said, "This system, I think, has been much kinder to the physician/patient relationship and to the physician's practice of medicine than the fee-for-service system."

Traditionally, nurses have worked within practice guidelines; thus, it is perhaps not surprising that the nurses in the focus groups were more positive about such guidelines than were physicians. Both provider groups saw benefits in practice guidelines but were concerned that "cookbook approaches" to the delivery of medicine could be dangerous for individual patients. Interestingly, among the three groups, consumers were the most adverse to practice guidelines. Discussion revealed that consumers believe practice guidelines would depersonalize care.

Both nurses and physicians expressed concern that managed care patients may be less prudent health care consumers since they either do not have out-of-pocket expenses or have extremely small co-payments.

Consumer participants seemed to suspect that treatment decisions were being made solely to save money. Several providers pointed to the influence of the media in increasing consumer expectations and demands on the health care system, as well as creating negative perceptions of managed care. Consumers pointed out that in managed care, they increasingly need to be aggressive to receive necessary information and care. Concerns were also expressed about

- the need to determine and implement the most efficient and cost-effective uses of developments in biomedical technology
- the need to protect patient confidentiality;
- the need to administer pre-certification procedures which are timely and efficient and facilitate care rather than operate as roadblocks to care
- the need to assure reasonable access to care through convenient provider locations, hours of operation and sufficient appointment availability

The focus group information was taken up with a national steering committee.

Steering Committee

The steering committee's functions were to recommend issues to be investigated by the task force and to recommend ethics standards to be required of managed care organizations seeking accreditation.

The steering committee was composed primarily of national leaders in health and managed care. Represented on the steering committee were the National Committee for Quality Assurance, Group Health Association of America, CIGNA, Kaiser Foundation Health Plan, Inc. of California, Blue Cross and Blue Shield Association, the American Academy of Family Physicians, the Picker Commonwealth Fund Project on Patient Centered Care, the University of Missouri-Kansas City School of Medicine, and the Center. (The membership list is attached.)

In May, 1994, the steering committee met for the first time to review the information collected in the focus groups and to discuss the groups' concerns.

The steering committee was asked to select three to four issues to be considered by a task force of managed care providers and ethicists. Ultimately, their message was that the overriding ethical issue in managed care is allocation of resources. Steering committee members

concluded that concerns voiced in the focus groups were subsumed under the allocation issue.

Once the task force convened and was meeting regularly, the steering committee continued its oversight and contribution through conference calls among groups of committee members. During the conference calls the work of the task force and the evolving task force document were discussed.

The steering committee met once again in January, 1995, to discuss the completed task force document and to formulate ethical standards to be required of managed care organizations seeking accreditation.

Task Force

Over a six-month period, a group of approximately two dozen professionals, all either involved in or interested in managed care delivery, met to critically reflect on ethical issues managed care organizations need to consider to allocate resources equitably. The group included clinicians, administrators, lawyers, ethicists, theologians and educators. (The roster is attached.)

The goal of the task force was to create this document. The document is intended to provide guidance for managed care organizations and to assist the steering committee in formulating recommended ethics standards for accreditation. Selected readings in ethics and managed care were distributed as background as the group worked through the issues. (A bibliography is attached.)

The task force met biweekly for four-hour structured dialogue. To begin the process, the group was asked to engage in an open discussion of ethical problems in managed care, to state assumptions, to define terms, and to discuss ethical principles. Between meetings, staff from the Center interpreted and synthesized the group's work by creating and subsequently revising the draft document.

Task Force Report

Ethical Foundations

When people perceive a disparity between "what is" and "what ought to be," ethical tension results. Attempting to reconcile that tension — moving the "is" toward the "ought" — is the process of "doing ethics."

The first step for the task force members as they began to "do ethics" together, was to describe the "is," the reality of managed care, as the task force members experienced it. From the beginning, it was apparent that group members perceived some inconsistencies

between the way managed care is delivered and the way group members thought it ought to be delivered. Having identified those inconsistencies, the group members then needed to agree on the appropriate ethical underpinnings of what they believed to be the ideal.

The task force agreed that the bedrock of their ethical thinking is respect for persons. Among the criteria for “respecting persons” are at least the following five ethical principles. These are widely accepted in the field of bioethics. None of the principles is absolute; each is qualified by the others. Additionally, principles must always be considered and weighted in the context of the particular decision.

Autonomy: managed care organizations and their providers have a duty to respect the right of their members to make decisions about the course of their lives.

Non-maleficence: managed care organizations and their providers are obligated not to harm their members.

Beneficence: each member should be treated in a manner that respects his or her own goals and values; managed care organizations and their providers also have a duty to promote the good of the members as a group.

Justice/equity: managed care organizations and their providers should allocate resources in a way that fairly distributes benefits and burdens among the members.

Promise keeping/truthtelling: managed care organizations and their providers have a duty to present information honestly and are obligated to honor commitments.

These principles are important touchstones in ethical decision making and are the underpinning of statements of rights, duties and obligations. However, there are other ethical concepts that merit consideration, the most important being the concept of virtue.

Virtues are traits of character generated by community and tradition which dispose individuals to act well. Thus, virtues are those values that, when inculcated into an individual, create “a habitual disposition to act well” (Aristotle). Aside from behaving virtuously toward its members, there are many ways a managed care corporation can act virtuously toward the community at large, such as adopting corporate policies which encourage health care professionals to provide uncompensated care, responding to community needs in time of crisis (flood, fire, earthquake, etc.), and offering community outreach programs.

A considered balance of ethical principles and virtues can promote better ethical decision making than grounding decisions on either alone. This document is based primarily on the ethical principles set out above, but the virtues of integrity, respect, and compassion have not been ignored. In the same way that it is the foundation of all positive human relationships, virtuous behavior is inherent in the caring aspect of health care. An emphasis on caring is both unique and ethically imperative in the delivery of health care.

Definitions

Early on, the members of the task force discovered that terminology is not used consistently from one delivery setting to another. Additionally, some terms had such negative connotations for some task force members that they did not want the terms included in a document about managed care. To address these issues, the task force members negotiated a list of functional definitions so as to have an agreed-upon common language with which to work. Discussing the terminology and thrashing out definitions helped to establish a working culture.¹

For example, when we began to discuss the term “gatekeeper,” it became clear that there were many different conceptions about this term and that some were emotionally charged. One view of a gatekeeper is a primary care provider striving to secure appropriate, cost effective care; another view is an individual, sometimes a nonclinician, intent upon obstructing access. To resolve these differences, task force members agreed to define gatekeeper neutrally as “a provider in the role of authorizer of services.” It is interesting to note that at the conclusion of the task force’s work, the term “gatekeeper” did not appear anywhere in the document other than in the definition section.

Another example of a highly charged term is “rationing.” Some task force members argued that managed care plans are not permitted to ration resources. Others argued that managed care routinely rations resources. These extremes reflected significant confusion between allocating care and rationing care. Ultimately, the task force resolved the confusion by using the term “allocating” resources when deciding how designated resources are to be distributed; whereas “rationing” would be used when a beneficial resource must be limited due to unavailability or excessive cost.

The task force is not recommending the adoption by any other group of the definitions they agreed upon.

Assumptions

To stimulate and guide our thinking, task force members listed basic assumptions about the delivery of health care upon which they could agree. These efforts resulted in statements we believe to be factually true as well as statements we believe *should* be true.

In the course of our work, the list of assumptions became the organizing core. Time and again as the group searched for consensus, we revisited these assumptions. They became criteria by which to test our consistency. When we found inconsistency, we either reconsidered the point or revised the assumption itself.

1. Every person is equally entitled to basic health care.

The group agreed that health care is a basic right. Health care was seen by the group as a moral entitlement. However, the task force could not agree about what ought to be included in “basic health care.” There were extensive discussions about what ought to be included, who should make such decisions and how basic health care should be paid for. Our lack of agreement reflected society’s inability to resolve these critical social issues.

2. Health care resources are limited.

The group agreed on this assumption while recognizing that there are others who believe eliminating waste and inefficiency would provide sufficient resources to meet all health care needs.

We were concerned that neither providers nor consumers yet fully recognize the influence of prepayment on health care decisions and the allocation of resources. Our society has generally accepted the questionable idea in health care that “more is better.” As we move toward a health care delivery model in which resources are finite and must be fairly and appropriately allocated, there is an urgent need for education and re-orientation of both providers and the public. All of us need to understand that more health care is not necessarily better health care.

3. Societal demand for health care is increasing.

The needs of aging and underserved populations, technological advances, increasing consumer expectations, and changing patterns of disease contribute to the increasing demand for and cost of health care.

4. Health care should promote wellness and treat disease.

Although managed care already offers preventive care and promotes wellness, members of the task force felt such programs have not been fully utilized. In discussion about how to motivate

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members to adopt healthy lifestyles, concerns were raised about the potential for coercion through negative incentives.

5. Value conflicts in health care are pervasive.

Ethical dilemmas occur when people experience value conflicts, either internally or among individuals. Increasing biomedical technology, legal intervention in health care, concerns about cost and new delivery models have intensified the potential for the conflict of various belief systems. These issues are compounded in a pluralistic, diverse society. Even persons of good intention and with similar value systems may have different perspectives which require resolution.

6. Each member covered by the same contract should have equal access to the same benefits.

The principle of justice requires that persons in similar situations should be treated similarly. Task force members shared experiences about plan members covered by the same contract who were treated differently due to perceived power, influence or status. Task force members believed strongly that such treatment is not only unethical and inequitable but is inconsistent with the underlying concepts of managed care.

7. Ethical issues may vary among managed care models.

The term “managed care” identifies a spectrum of systems, ranging from so-called managed indemnity plans through PPOs, point-of-service, open-panel HMOs, and closed-panel HMOs. Although ethical principles remain the same for all models, the impact of certain issues or specific concerns may vary from one model to another.

Repeatedly, as the task force members considered the importance of the provider/patient relationship, concerns surfaced about the impact on that relationship of financial incentives—in any system, managed care or fee-for-service. Fee-for-service financial incentives may lead to overtreatment; financial incentives in managed care may lead to undertreatment; both are improper.

Focusing on managed care, the group recognized that managed care providers have a duty to be prudent users of health care resources, yet emphasized that a provider’s primary duty is to act in the best interest of the patient, which is an application of the principle of beneficence. Beneficence is strained when the best interest of the patient is adversely influenced by economic incentives. Of special concern are systems where providers are finan-

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cially influenced in response to limiting necessary care in individual cases.

Other examples of how ethical issues vary among managed care plans are reflected in this document; however, none were considered as important as the issue of financial incentives.

8. Individual autonomy is often limited in health care because contracting for care is dominated by employers and government.

Autonomy became an important issue when the task force discussed member and plan responsibilities. The plan must accept responsibility for supporting the autonomy of members through recognizing member rights because the consumer has little power to choose health plans or to negotiate the health care contract between the member and the plan. For the same reasons, placing responsibilities on the membership would be unfair; thus, members should have fewer responsibilities than does the plan or its providers. The rights and responsibilities section of this document reflects this rationale.

9. An effective plan is one which balances the conflicts inherent in managed care among members, providers, and managers.

The task force members clearly believed that managed care plans concerned with quality and fiscal soundness are concerned with ethics and are willing to attempt to create a culture that supports ethical sensitivity and behavior. The fee-for-service autonomy-driven ethical model will not suffice; the good of the entire membership, balanced by fairness and equity, must be included.

10. Members should be aware that managers and providers allocate resources as a method of balancing the potentially conflicting interests of individual members, the membership as a whole, providers and the plan.

Consumers need to be educated about the shift in financial incentives and payment mechanisms that can influence health care treatment decisions. Health care today relies on an informed consumer. Because a managed care plan is an integrated system of delivery, care is enhanced when members know how to interact with the system and advocate for their own interests.

11. Although the primary focus of health care is the individual, providers have professional duties and obligations to the membership as well. There may be instances in which these duties and obligations are in conflict.

Health care professionals, when trying to balance their duties and responsibilities to the member with their duties to the membership, find an absence of fixed rules for making these difficult judgments; rather, providers should exercise the virtues of integrity, respect, and compassion. Managed care plans should promote an organizational culture that nurtures these virtues.

12. The distinctions among beneficial, marginal, futile, alternative and experimental care are ethically relevant when allocating resources and making individual treatment decisions.

Early in our discussion, task force members thought that clinical definitions for the above categories of care would assist in the search for an ethically defensible way of allocating resources. No one thought it appropriate to deny care that was clearly beneficial, nor did anyone believe it would be necessary to provide futile care, i.e., care without benefit. However, the judgment required in each clinical situation is resistant to rigid prior definition. Specific criteria must be kept fluid enough to interact with less objective, yet compelling, value factors. This same competitive interaction of facts and values is relevant to resource allocation at the macro and micro management levels. We recognized that each plan needs a deliberative process by which treatment options are determined to be beneficial, marginal or futile, experimental or fit other criteria.

13. Managed care plans determine when care is medically necessary and, thus, will be covered. This process assumes agreed-upon standards of care by which to measure appropriateness of care. There is only minimal consensus about the standards used to make these determinations by managed care plans at this time.

Physician members articulated to the group that there are few nationally accepted standards of or guidelines for

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care at this time, and that the development of such standards is a tedious and uncoordinated process. Managed care plans should participate in developing uniform data collection methods to gather comparable scientific information for use in creating clinical standards of care.

14. Both competence and compassion are important in the delivery of quality health care.

Quality of care as well as compassionate delivery of care can be endangered by failure of communication. As more attention is given to the management of health care, the importance of the caring aspect of medicine may be diminished and health care may become more depersonalized. Repeatedly, task force members stressed the importance of caring and compassion.

15. A caring relationship between a competent, empathic provider and the member is essential to the provision of effective health care services; the relationship must be encouraged and protected.

Task force members discussed the negative impact of disrupted provider/patient relationships which can result when plans frequently change the panel of providers or when employers frequently change plans. The value of sustained provider/patient relationships needs to be considered strongly; making decisions for economic reasons only which disrupt provider/patient relationships is not acceptable.

Creating an Ethical Corporate Culture

As health care becomes more competitive, it is essential for health care providing organizations to highlight ethical concerns by formally integrating ethics into quality improvement.

To support an ethical environment, plans should:

1. Encourage honest, effective and open communication between the plan, potential members, providers, members, and members' families.
2. Adopt and honor statements of rights and responsibilities for members, providers, and the plan.
3. Educate members about how the system works.
4. Educate employees, providers and members about ethical issues and the mechanisms the plan has available for understanding and responding to those issues.
5. Have policies and procedures in place to provide guidance to providers and members confronted with ethical issues. Providers and members must be involved in developing and implementing these policies and procedures.
6. Develop and maintain a culture where ethical considerations are integrated into decision making at all levels.

7. Ensure that organizations with which they contract have policies, procedures, and practices which are compatible with those of the plan.
8. Develop formalized methods for managing ethical conflicts. Some plans may choose to establish ethics committees; others may use bioethics consultants or network with other organizations who have expertise in this area.

The Role of Ethics Committees in Managed Care

Ethics committees became an accepted entity in hospitals in the 1980s as a way to empower patients to participate in a shared decision-making model. They are multidisciplinary, often include consumer members, and act in an advisory capacity. Their role and functions are generally understood to be

- ethics education
- policy development/review, and
- case consultation

They typically meet monthly to provide a forum for the discussion of ethical issues and to promote education within their organizations. It is common for ethics committees to be of assistance to administration by reviewing and at times generating policy statements. Ethics committees are available to providers, patients and their families for the discussion of conflicted clinical situations. Ethics committees have been slow to evolve in managed care organizations although they do exist and are helpful within some plans. Further, some managed care plans have bioethics consultants and many participate in ethics committee networks.

The attention given to the case consultation aspect of ethics committees gives unwarranted importance to this function when in fact from the organization's point of view the other functions may be more useful. Task force members believe that grievance mechanisms in managed care organizations may have substituted for the case review aspect of ethics committees. This may have inhibited the development of ethics committees in managed care.

However, every managed care plan faces a need for developing policies on issues with ethical implications. Ethics committees are well suited for recommending and evaluating policies that facilitate ethical practice in managed care. Ethics committees have also been successful in education about policies. Task force

members identified the following traditional issues and others they considered specifically relevant to managed care, all of which may require policy consideration.

Traditional Ethical Issues

1. Informing patients about their right to make advance directives and honoring advance directives, i.e., verbal or written expressions of a member's wishes made in the event that the member no longer has decisional capacity. Living wills and durable powers of attorney for health care decisions are examples of advance directives
2. Determining the ability of the member to make decisions, i.e., decisional capacity
3. Designating surrogate decision makers for persons without the ability to make treatment decisions
4. Obtaining informed consent to treatment, including

Statements of rights and autonomy are an attempt to give substance to the ethical principles of autonomy, beneficence and justice . . .

respecting the right to refuse treatment

5. Obtaining informed consent from members being asked to participate in clinical research
6. Withholding or withdrawing life-sustaining treatment, e.g., denying futile treatment and deciding not to provide cardiopulmonary resuscitation (CPR)
7. Respecting cultural and religious differences that influence treatment decisions
8. Maintaining privacy and confidentiality
9. Providing appropriate palliative care for dying person

Ethical Concerns of Special Interest to Managed Care

The following list is not a comprehensive or total list. Other issues which may be of concern include the social mission of the organization; professionalism and profes-

sional relationships; and education and communication with members. This list does, however, contain the ethical issues which should be addressed in any managed health care environment.

1. Evaluating treatment alternatives, including determining whether to cover new treatment
2. Limiting self-referral and utilization options for members
3. Limiting referral and utilization options for providers
4. Facilitating access to appropriate care
5. Credentialing and retention of providers through a fair and reasonable process which maximizes quality of care and professional competence²
6. Minimizing potential conflicts of interest which may arise from provider compensation and incentive methods

Rights and Responsibilities of Members, Providers, and Plans

Statements of rights and responsibilities are an attempt to give substance to the ethical principles of autonomy, beneficence and justice and can be a helpful screen for determining whether an action is ethical.

Members' Rights

All health care accrediting organizations require attention to patient/member rights. The task force reviewed a variety of rights statements and incorporated them into the list below. New rights have been added and statements of responsibilities for plans and providers have been developed.

Members have a right

1. To be treated with respect, which includes the right to have expressed cultural and spiritual values and beliefs respected
2. To be treated equitably regardless of race, color, religion, sex, age, national origin, ethnicity, sexual preference, lifestyle choice, disability, or geographic location
3. To choose a primary care provider from the panel of available providers
4. To receive services in response to medically appropriate and reasonable requests which are within the responsibility of the organization

5. To receive relevant information, in language(s) the member can understand, regarding the member's clinical condition, including diagnosis, prognosis, and treatment options
6. To access the member's medical records and to an explanation of all information contained in the records
7. To have any proposed procedure or treatment explained in language(s) the member can understand, including descriptions of:
 - the nature and purpose of the treatment
 - possible benefits
 - known serious side effects, risks or drawbacks
 - the recovery process, including potential problems associated with recovery
 - likelihood of success
 - optional procedures or treatments, including non-treatment; and
 - any additional costs for which the member may be responsible
8. To participate in treatment decision making, which includes the rights
 - to accept or refuse any procedure, drug or treatment and to be informed of the possible consequences of any such decision
 - to a second opinion within the context of the plan
 - to appeal treatment decisions within the grievance process
 - to request consultation regarding ethical issues surrounding care from an ethics committee or other appropriate source
9. To give informed consent to treatment, or if unable to consent, to have consent obtained from a surrogate decision maker
10. To give informed consent to or to refuse care that involves research, experimental treatments or educational projects
11. To make advance treatment directives, including the right to name a surrogate decision maker in the event the member cannot participate in decision making

12. To voice grievances about the managed care organization (or care provided) through an internal grievance procedure
13. To receive education and relevant information, in language(s) the member can understand, about the managed care plan, its services, and the practitioners providing care, such as
 - names, qualifications and titles of providers
 - benefits and services included and excluded
 - procedures for choosing and changing practitioners
 - access, including out-of-plan coverage;
 - charges the members may incur
 - scheduling information
 - referral procedures
 - termination of membership and denial of claims
 - grievance procedure
 - conflicts of interest, including financial incentive arrangements, which may impact access to care³
 - ethics consultation
 - corporate nature of plan, i.e., for profit or not-for-profit
 - data regarding outcomes and quality; and
 - health education
14. To have personal privacy respected, in that care discussion, consultation, examination and treatment will be conducted discreetly
15. To have all communications and records related to care kept confidential except for those persons who have a need to know because they are participating in the delivery of care, or in resolving claims or grievances
16. To know that employers and other payers will not be given access to clinical information about individual members without permission of the member, except where otherwise provided by law
17. For members who are minors, to participate in treatment decisions to the extent of their capacity including giving informed consent

Member Responsibilities

There was vigorous discussion about this section. The reader will note that the list of member responsibilities is shorter than the proposed list of rights. The views of task force members varied from a minority who wanted no explication of member responsibilities to those who wanted a great deal more than those appearing here. The primary reason for this variance, as stated in assumption seven (7) above, is that the member does not have the power to negotiate responsibilities.

Many on the task force pressed for a model of health care delivery in which the consumer participates to the fullest extent possible, including accepting a share of responsibility.

While the extremes could not be reconciled, there was consensus that the right to health care cannot be denied on the basis of failure to live up to member responsibilities.

Members have a responsibility, to the extent of their capacity:

1. To participate in decision making
2. To seek and give needed information to providers
3. To follow mutually agreed-upon treatment plans
4. To notify providers when treatment plans will not be followed, are not followed or are not effective
5. To use the plan's preventive and early intervention programs

Provider Responsibilities

The provider's primary ethical responsibility is to provide care with integrity to the member in a respectful and compassionate way. Providers have responsibilities to the plan and to the members.

Providers have a responsibility to

1. Respect member rights
2. Disclose to the member treatment options not covered by the plan which may benefit the member
3. Give priority to clinical and scientific information over financial data
4. Adhere to the plan's standards of care or, where the provider judges the standards not to be in an

individual member's interest, to advocate another treatment option to the plan

5. Provide information so that the member can give informed consent for treatment; when the member is unable to participate in decision making, solicit consent from an appropriate surrogate.
6. Encourage and assist members to make advance directives and assure that directives are honored within the confines of state law
7. Educate and encourage members to maintain health and use preventive and early intervention services
8. Educate and encourage members to use the plan's resources prudently, in a manner that reflects concern for the needs of all the plan's members⁴
9. Use prudently the resources allocated by the plan
10. Participate in allocation policy development for the plan and practice within the plan's allocation guidelines
11. Participate in the development, implementation and revision of clinical guidelines and standards of care
12. Participate in the collection of outcome and quality assurance data
13. Participate in the selection and credentialing of providers
14. Speak out and resist when unethical practices are being pursued by peers, purchasers, or the plan. It is not enough to quit the plan; the provider should also work to see that the practice is ended
15. Treat members without regard to reducing the provider's financial exposure or maximizing the provider's financial gain
16. Permit the member to have access to the member's medical records and to explain all information contained in such records
17. Keep confidential all communications and records related to care except for those persons who have a need to know because, for example, they are participating in the delivery of care, in quality assurance or in resolving claims or grievances
18. Deny access to employers and other payers to clinical information about an individual member

unless permission of the member is obtained, except where otherwise provided by law.

19. Conduct care discussion, consultation, examination and treatment discreetly in order to respect personal privacy.

Plan Responsibilities

The extensive plan responsibilities list should provide guidance for the construction of a system for the ethical management of care. The care with which this list of responsibilities was developed emphasizes the importance task force members placed on organizational ethics and the need to create a structure in managed care organizations that supports ethical sensitivity and behavior.

We also believe the weight of responsibilities for the plan versus those for the provider reflects an ongoing shift in power, responsibility, and authority in health care delivery.

The plan has a responsibility to

1. Respect and honor member rights.
2. Assess the health care needs of the membership and provide care commensurate with those needs.
3. Provide relevant information to providers, prospective members and members about benefits and limitations within the plan, and outcomes data, when available.
4. Provide equitable care to all covered members in a fiscally responsible manner.
5. Minimize financial pressures that encourage providers to make treatment decisions on economic grounds rather than clinical criteria.
6. Determine whether providers are basing treatment decisions on financial considerations and take appropriate action.
7. Provide adequate resources (including adequate time with patients), information, and professional development so that providers can fulfill their obligations to members.
8. Provide mechanisms so that providers can participate in the development, implementation, and revision of clinical guidelines and standards of care.
9. Choose to cover or exclude treatments on the basis of appropriate clinical information, developed through

objective measures of clinical research, where available, and cost effectiveness.

10. Provide quality care and improve care by participating in continuous quality improvement.
11. Engage in standardized data collection and reporting activities.
12. Promote continuity of care through coordination of services and avoiding unnecessary disruption of the provider/member relationship.
13. Educate and encourage members to maintain health.
14. Provide preventive and early intervention services.
15. Choose and retain compassionate, caring, competent, credentialed providers who are prudent users of plan resources, committed to continuous

Many on the task force pressed for a model of health care delivery in which the consumer participates to the fullest extent possible, including accepting a share of responsibility.

quality improvement and who adhere to quality guidelines and measures.

16. Provide a copy of policies regarding members' rights and responsibilities to providers and members, in the languages of the major populations served.
17. Have policies and procedures to assure that members are given appropriate information in order to give informed consent to treatment.
18. Involve minors and other members with reduced capacity in health care decisions to the fullest extent possible.
19. Provide information to members and persons considering membership about provider payment methods and incentives.
20. Educate members, staff, providers, and the com-

munity about advance directives and assure that directives are honored and forwarded to the appropriate setting, such as the hospital.

21. Have a timely and organized system for resolving member complaints, grievances, and concerns.
 - a. Complaints must be documented and analyzed to be used for quality improvement.
 - b. Grievances must be reviewed by a panel and must include an opportunity for the member to participate, as well as an opportunity to appeal.
 - c. There must be an expedited procedure for emergency cases.
22. Have a timely and organized system for members to obtain ethics consultations.
23. Eliminate unreasonable barriers to equitable access to covered care and services as a means of resource allocation.
24. Make available to providers timely access to utilization decision makers.
25. Provide a mechanism whereby members and providers can be involved in policy development.
26. Permit members access to their medical records and have all information contained in the records explained to them.
27. Keep all communications and records related to care confidential, except for those persons who have a need to know because they are participating in the delivery of care, in quality assurance or in resolving claims or grievances.
28. Build ethics into the organization by providing to all staff education that promotes ethical practice.

Ethical Guidelines for Allocating Resources

There are inherent tensions in health care delivery caused by unlimited demands and limited resources. Ethical tension results from inability to fully satisfy these competing claims. To ameliorate this tension, the interests of the membership, the individual member, the plan, the providers, and the payers must be fairly balanced in making allocation decisions.

The task force attempted to create a mechanism for allocating resources in an ethically defensible manner. The first part of the mechanism is a checklist of rights

and responsibilities, similar to that above. If an allocation decision does not violate a right or leave a responsibility unfulfilled, there should be some confidence that the decision is ethically defensible. Such a checklist provides a simple way of applying ethical principles to allocation decisions and may be a helpful first level screen. However, when a decision violates a member's rights or is inconsistent with an explicated responsibility, a more complex guideline is needed. Such a guideline would promote an extended deliberation about the moral implications of the decision. Should both approaches fail, the task force outlines methods of managing unresolved conflicts.

The following is a list of guidelines to use if a deliberative process is necessitated by the inadequacy of a rights and responsibilities statement:

1. *The basic ethical criterion for the planned allocation of resources in a managed care setting at the policy level is the well-being of the entire group for whom the decisions are being made, balanced by the requirement to respect individual health care needs.*

This criterion expresses the tension between the ethical principles of respect for individuals and consideration of the well-being of the group. It is counter to the autonomy-driven medical ethic which has been the dominant model in the United States since the mid-60s. The inherent risk of moving toward consideration of the well being of the group, which is a more communitarian ethical model, is that in order to benefit the membership as a whole, the rights of individuals and the just needs of the seriously ill might not be met. To avoid this danger, sensitivity to needs of the most vulnerable should be maintained.

2. *The plan is not obligated to provide unlimited resources to any individual member (except for medically necessary treatment covered by the plan).*

Plans are not required to provide all the treatment that may be available or requested. Managed care plans provide care that is "medically necessary" within the terms of their contracts. The ethical dilemma occurs when considering treatments which are not clearly "medically necessary" or a covered benefit. To make judgments to deny requested care, managed care plans must have a clearly delineated mechanism applied evenhandedly.

3. *Each member covered by the same contract should have equal access to the same benefits.*

Providing equal access is basic to every managed care organization both from a business perspective and from an ethical point of view. Task force members believe that equal access should not be distorted by granting special advantages to a privileged few. As stated in assumption 5, similar situations should be treated similarly.

4. *No member should be denied medically appropriate healthcare because of race, color, religion, sex, age, national origin, ethnicity, sexual preference, lifestyle choices, disability, or geographic location. (There are circumstances in which some of these differences are clinically relevant and should be considered in treatment decisions.)*

There was solid agreement about this guideline. However, on several occasions there was intense discussion about whether incentives to alter lifestyle choices or behaviors could be justified. A fair amount of frustration was expressed by the clinicians about their inability to help people who refuse to help themselves. Both positive and negative incentives were considered. Labeling an

Every plan should have a mechanism in place to minimize biased decision making in evaluating policies.

incentive positive or negative, of course, depends on one's point of view. (An example of an incentive which is positive from one viewpoint and negative from another would be to offer a lower premium to smokers who quit. Those who quit get a positive incentive (lower premiums) those who do not get a negative incentive (the punishment of paying a higher premium). Ultimately, task force members agreed that negative incentives in the healthcare setting are impermissible because they are clearly too great a threat to individual autonomy. However, there are times when positive incentives may be justified on a benefit/burden basis. A reward for changing behavior may be an investment that results in significant future benefits for the individual and for the entire membership.

5. *Every plan should have a mechanism in place to minimize biased decision making in evaluating policies.*

Because policy decisions are never value-neutral, plans need a mechanism to balance scientific and subjective information. Some factors that should be considered when making policy decisions are:

- Regulatory and statutory requirements;
- Scientific information and qualified professional input, including clinical studies and life quality studies where available;
- Member input to reflect the needs and the values of the membership;
- Unique or special circumstances including gender, culture and ethnic diversity; and
- Costs.

6. *Policy decisions about the allocation of resources should include consumer input.*

Even with the best of intentions, providers and plan managers may not know what the membership would want. Therefore, plans should solicit consumer preferences. While agreeing that consumer input is valuable, task force members disagreed about the appropriate degree of involvement and appropriate ways to involve consumers in policy decisions.

7. *Policy decisions about the allocation of resources should also include the input of plan providers.*

Health care providers are in a unique position to contribute to policy development for the following reasons:

- Providers understand the basic nature of the

Everyone involved in conflict resolution activities should be provided some education in ethics.

clinical relationship and the impact of the managed care model on that relationship.

- Provider input is important in evaluating clinical outcomes and improving allocation decisions.

- Providers are in a position to interpret allocation policies to members.
- Providers who contribute to the design of the system will be more committed to it and more capable of applying it.
- Providers can help members understand the limitations of the plan.
- Providers should help consumers advocate for their own care.

Dealing with Ethical Dilemmas/Conflicts Regarding the Allocation of Resources

Ethics is often thought of in the context of conflict; however, members of the task force strongly believe that, like all other health care providing organizations, plans should strive to build ethics into their structure and culture by providing education and promoting ethical practices throughout the organization. Everyone involved in conflict resolution activities should be provided some education in ethics. Education and development of ethical policies are traditional functions of ethics committees. However, when conflict does occur, because conflicts and dilemmas are inherent in the delivery of health care, plans will need organized ways of dealing with it. Some conflicts are predictable. Providers and members often can assist plans in predicting where ethical concerns and value conflicts may arise.

Resolution of Ethical Conflicts

1. Because of the power imbalances among the members, providers and the plan, the individual member's needs may have to be emphasized in resolving ethical conflicts.
2. A formalized process needs to be in place to resolve ethical conflicts. This process should be well known and available to providers and members.
3. If appropriately trained in ethics, the following persons may be useful in resolving conflict:
 - a. Ombudsman services
 - b. Patient representatives
 - c. Chaplains
 - d. Social workers

- e. Grievance procedures
 - f. Mediators outside the plan
 - g. Ethics consultants
 - h. An ethics committee
4. Court intervention should be seen as a last resort.

Future Issues

In the course of the task force's work, issues surfaced which brought about significant discussion yet were thought to be beyond the scope of the task force. Additionally, task force members were unable to reach consensus on all issues. However, as health care is in the midst of tremendous transformation, task force members believed it important to mention several of these issues, including: rationing, consumer involvement, corporate social responsibility, professional education,

*It is never ethically defensible
to ration palliative care.*

research, the importance of professionalism and the pursuit of ethical practice at both the corporate and the clinical level.

Rationing

Rationing as an integral part of country-wide health care decision making has not become a reality in the United States, as it has in Great Britain (although the Oregon plan for Medicaid recipients in that state explicitly rations and limits care that will be provided by the Medicaid program).

Even though rationing in this broad, society-wide sense is not directly relevant to managed care in its present form, the members of the task force returned to the subject so often and were so intensely interested in making a contribution to the rationing dialogue, that the task force decided to emphasize that when the time for society-wide rationing comes, ethical considerations should not be lost in the discord sure to arise. We believe the time must come when difficult decisions, including accepting some forms of rationing, will have to be made in order to live within limits on health care resources.

Some in our society believe the health care system can provide unlimited care to everyone far into the future,

and others believe elimination of fraud and waste would ensure sufficient health care resources in the future without rationing. We hope they are right; if they are not, we emphasize the necessity for our society to make rationing decisions based on ethical considerations, be they in our formulation or some other. The task force members believe the ethical considerations set out here offer a reasonable approach to reaching ethically defensible rationing decisions when such decisions are debated in the future.

Considerations for Ethically Rationing Care

- Caring is an ethical imperative for health care providers because it is an essential benefit.
- The first duty or obligation of any health care professional is to provide treatment that is clearly of benefit.
- It is never ethically defensible to ration palliative care.
- "Futile" treatment is of no benefit and should not be provided. However, care must be taken when defining a treatment as "futile" that the point of view of the patient is considered.
- Treatment of marginal benefit needs to be carefully evaluated so that decisions are not inappropriately influenced by concerns such as subjective quality of life judgments of anyone other than the patient, cost constraints or defensive medicine.
- Individuals should make for others only those rationing decisions they are willing to impose upon themselves.
- Populations that are especially needy or vulnerable should be given special consideration in order to be able to compete for the benefits society has to offer.
- In rationing decisions, people ought not to be discriminated against without cause. Criteria that have been avoided by our society in such decisions, e.g., age or gender, may be ethically considered when clinically relevant.
- Lifestyle choice in and of itself is not a reason for denying care. However, it is ethically justifiable to provide positive incentives to support the development of healthy lifestyles.

Developing Hierarchies for Rationing

All rationing plans include some kind of prioritizing schema. Some of the factors that have been used for establishing such priorities include age, social worth, cost, availability, and efficacy. Task force members are proposing that rationing plans be based on concepts of justice and utility, i.e., rationing schema should necessarily consider that which provides the greatest good to the greatest number of people while maintaining respect for individuals and being mindful of fairness and equity.

The currently best-known example of a schema for allocating health care resources is the initiative in Oregon where health care treatments for Medicaid recipients have been prioritized based on a complicated calculus involving factors of benefit, duration of benefit, quality of well-being and costs.

An alternative methodology to the Oregon plan is one published by Daniel Callahan, Ph.D., in *What Kind of Life* (Simon and Schuster 1990), in which Callahan proposes the following basic rationing hierarchy:

- Caring in its most basic forms, e.g., palliative care
- Public health, prevention and wellness programs, e.g., immunization and pre-natal programs.
- Emergency treatment
- Primary care, e.g., antibiotics
- Advanced forms of medical cure and restoration, e.g., chemotherapy for infantile leukemia.
- Technologically advanced medical therapy, e.g., multiple organ transplantation
- Experimental treatment

External Social Responsibilities

Issues listed below were frequently part of the task force discussion. However, they were seen as societal issues beyond the responsibility of any single plan, even though some plans currently participate in many.

However, the task force could agree that as managed care expands to a dominant position, there will be an increased social expectation that all plans will support and participate in activities such as:

1. *pro bono care*
2. *public health care* such as health screening and immunizations

3. *professional education and training* for current and future providers
4. *community health education*, including improving consumer access to medical libraries and computer databases
5. *health related research*
6. *open collegial relationships* among health care professionals and between plans in order to mitigate the effects of competition on the *exchange of professional knowledge*.⁵

Internal Responsibilities

The following were issues task force members believed could not be resolved in the context of this project but could agree warranted further consideration.

1. Protect consumer interests by *increasing member input and accountability of plans to members*.
2. Protect provider interests by supporting *due process* in provider disciplinary and removal procedures.
3. For large national managed care organizations, enhance *local decision making* through local advisory boards.

Notes

1. Since the definitions were not intended for a general audience, they are not included in this report. Anyone interested in the definitions can request them from Midwest Bioethics Center.

2. Due process was an issue which provoked repeated discussion that did not lead to consensus. Task Force members were divided on whether due process procedures should be required when removing physicians for negligence or incompetence; a larger number of the task force felt removal for failing to meet the plan's economic expectations should not require due process procedures.

3. The point(s) at which members should receive information about provider financial incentives peculiar to managed care and their potential for creating conflicts of interest provoked heated debate. Task force members could agree that such information is important to know before deciding whether or not to join a managed care plan.

In addition, some task force members believe a physician has an ethical obligation to explain to each patient at the initiation of a treatment relationship the differences between fee-for-service and managed care financial incentives and the resulting potential for conflicts of interest between the physi-

cian and the member. Others responded that such a discussion would undermine trust and thus weaken the physician-patient relationship. Although the question came up again and again, consensus could not be reached.

4. An example of prudent, considerate use of the plan's resources would be calling to cancel an appointment, thus freeing the time for another member's use.

5. As competition between managed care organizations increases, new medical knowledge may be thought of as proprietary, thus endangering collegial relationships among physicians and stifling the flow of information.

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