Expanding the Scope of Nursing Ethics: Cost Containment, Justice and Rationing

by Martin Benjamin and Joy Curtis

The scope of nursing ethics must be expanded from a traditional view that focuses primarily on individual clients to one that incorporates questions of cost containment, social justice and the possibility of health care rationing. This essay outlines the following: (1) cost containment and the claims of justice, including an examination of health care as a consumer good and expected effects of reducing waste and inefficiency; (2) access to care; (3) the concept of rationing; and (4) an ethical framework to assess rationing that includes elements of fairness in allocation, contractualist justification, and respect for persons. The discussion uses case studies and examples.

Nursing ethics is expanding from an approach focused primarily on individual clients and their families to one that includes issues raised by escalating health care costs. This essay begins with a brief overview of current ethical problems in nursing and then outlines an expanded view that highlights the following: (1) cost containment and the claims of justice; (2) access to care; (3) the concept of rationing; and (4) an ethical framework to examine rationing schemes that includes fairness in allocation, contractualist justification and respect for persons.¹

Introduction

The study of ethics in nursing during the recent past has centered on direct patient care and the place of nursing in the health care system. Current study focuses on nurses and their work with individuals and families and includes, for example, discussions of parentalism, deception, confidentiality, professional obligations and conflicting claims. Current work also looks at nurses' relationships to other health care providers and studies nurse-physician relationships and dilemmas between nurses and nursing supervisors. Specific topics include nurse autonomy, collaboration, integrity-preserving compromise, conscientious refusal, determining responsibility and administrative dilemmas. Nursing ethics also discusses the nurse's personal responsibility for institutional and public policy, labor strikes, ethics committees, whistle-blowing and advance directives.

The nursing community, like society as a whole, faces ethical issues tied to soaring health care costs. Consequently, nursing ethics, which has focused

primarily on the patient and nursing's role in the health care delivery system, is expanding to address questions of cost containment, justice and rationing. Ethical dilemmas related directly to these issues increasingly occur in clinical nursing practice. The following, a case in which a nurse carries an overwhelming work load, is typical:

A nurse with four years' experience on a medical-surgical unit enjoys a good reputation as caring, competent and efficient. To accomplish assignments capably, safely, effectively and with care, she establishes priorities—which patient, which task, which sequence. But her daily work load includes so many tasks and so many patients who require time-consuming nursing activities that she simply has too much to do. For example, she believes that patients have a right to explanations and opportunities to ask questions; yet, even when she makes conversation brief and performs tasks as efficiently as possible, she must work overtime to provide minimally decent, safe nursing care. Troubled by the overwhelming work load, she is considering whether to quit her job. She is facing an ethical dilemma connected to her focus on individual clients: Ought she continue to work on the unit knowing that she is participating

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in a situation that requires her working overtime to maintain an adequate standard of nursing care? Moreover, she also faces ethical questions that expand the focus of nursing ethics to include cost containment, social justice and health care rationing. What, if anything, ought she do as an individual nurse to change this situation? What, if anything, ought she do as a member of a profession—at the hospital, community, state or national level—to address problems of health care cost and allocation?

1. Cost Containment and the Claims of Justice

The United States is experiencing rapidly increasing health care costs. Expenditure on health care in 1993 requires 14 percent of the nation's gross national product. At the same time the United States is facing an increasingly competitive international market. Other countries are able to produce goods more cheaply than the United States because, in part, of high-cost benefits for American workers. For example, Hillary Clinton reported that automakers in the United States currently spend \$1,100 on employee health care for each vehicle manufactured. According to Joseph S. Califano, American automaker employee health care costs are twice that of French and German and three times that of the Japanese. 3

Our nation, however, cannot continue to meet increasing health care expenditures without neglecting other claims such as education, job training, housing, environmental protection, and repair of the nation's infrastructure (roads, bridges, sewers, etc.). Nurses, like others in society, face the dilemma of limiting health care or limiting what we spend on other societal goods in order to meet soaring health care costs.

But, one could say, this dilemma need not exist if health care could be treated as simply another consumer good. Such a view, however, would be faulty. Health care differs from consumer goods or services such as designer clothing and camcorders because, like basic education, health care is necessary for maintaining genuine equal opportunity. A person cannot exercise his or her capacity to lead a decent life if restricted by ill health or poor education. Given our society's view of the importance of equal opportunity, treating health care as a commodity available to the highest bidder is unacceptable.

A second way of resolving the dilemma of limiting health care costs or funding health at the expense of other societal needs is to reduce waste and inefficiency in the health care system. According to Joseph S. Califano, "the evidence is now overwhelming that at least 25 percent of the money Americans spend on health care is wasted. And those wasted billions would be more than enough to fill the gaps and provide all the health and long-term care our people need." Califano cites as evidence overspending for tests and treatments that have little or no effect, inefficient hospital occupancy rates, a costly medical malpractice system, and the world's most expensive health care administrative system.

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Unfortunately, efforts to reduce costs and inefficiency do not eliminate the dilemma, because demands for expensive, high-technology medical treatments stretch to meet our elastic idea of what constitutes a medical "need." Medical needs and medical treatments expand in tandem. Development of new ideas has no natural limit and demands for new treatments seem inexhaustible.

In a discussion of medical progress, Daniel Callahan aptly describes its never-ending "ragged edge":

Imagine that you are trying to tear of piece of rough cloth and want to do so in a way that leaves a smooth edge. Yet no matter how carefully you tear the cloth, or where you tear it, there is always a ragged edge. It is the roughness of the material itself that guarantees the same result; a smooth edge is impossible. No matter how far we push the frontiers of medical progress we are always left with a ragged edge—poor outcomes, with cases as bad as those we have succeeded in curing, with the inexorable decline of the body however much we seem to have arrested the process. Whether it be intensive care for the premature newborn, low-birthweight baby, bypass surgery for the very old, or AZT therapy for AIDS patients, the eventual outcome will not likely be very good; and when, eventually, those problems are solved there will then be others to take their place. That is the ragged edge of medical progress, as much a part of that progress as its success.5

As long as society is willing to spend resources to find new ways to forestall death, we will have a "ragged edge" of medical progress with its challenges to develop expensive solutions to never-ending medical "needs."

Thus, while eliminating waste and inefficiency in the health care system will mitigate the problem of ever-increasing costs, such efforts will not contain those costs. Society will continue to face the dual problems of limiting costs while finding just ways to distribute access to health care.

2. Access to Care

Access to health care is not fairly distributed in the United States. Nurses know first-hand that not everyone has access to a basic level of care. For example, a city newspaper recently announced in a lead article entitled "Prenatal Care on the Critical List" that a local prenatal clinic faced closure. The clinic, organized to serve women without insurance, had been operating for twenty years with an all-volunteer staff who had cared for 2,720 women and delivered 1,956 babies. The current limited number of volunteer nurses would soon lead to the clinic's closing because funding for paid staff had not been found. The article further explained that no additional prenatal care in the city would be available through other local clinics serving low-income, Medicaid dependent women, and that only one doctor in the county was currently willing to accept new Medicaid patients.^o

This single picture of inequality in access to prenatal care is an example of a widespread situation. About 37 million Americans lack medical insurance. Many people who have low-paying jobs, especially in service-related fields, have little or no health care insurance and cannot afford to buy it for themselves. Medical insurance is costly; premiums require the equivalent of one-fourth the annual income of a family of four that earns only slightly more than the officially defined poverty level (\$12,675 in 1990). Lacking insurance, people lack access to health care, which results in their foregoing needed treatment and, thus, suffering the consequences. At special risk are children who make up 32 percent of the uninsured. 8

Given that justice demands that everyone be afforded equal access to basic care and that health care, even when trimmed of excesses and inefficiencies, will continue to include ever-improving but costly technology, society faces the prospect of health care rationing.

3. The Concept of Rationing

Nurses are familiar with the concept of rationing. For example, a nurse with a large caseload allots a certain amount of her or his time and energy to each patient. By providing each with at least minimally decent, safe care, she or he treats each person fairly. But rationing health care is more difficult than rationing nursing services among a specific caseload of patients because a nurse can base her activities on standards of care endorsed by the nursing community. The entire nation, however, has not agreed on what ought to count as an appropriate portion or fair allotment of health care which should be available to everyone.

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The difficulty of rationing health care is compounded by the nature of health care itself. First, health care needs vary widely among individuals. For example someone born with no disability and nurtured in a safe and happy community, may need but few health care services in a lifetime. Another person born with serious disabilities or deprived of good food and, perhaps neglected and abused, may need many health care services. Second, health care needs are difficult to distinguish from health care wants. For example, questions arise as to whether hairpieces for chemotherapy patients or infertility treatments for childless couples ought to be judged as needs or wants. Third, different aspects of health care compete for funding. For instance, the health care system includes not only acute care but research, health promotion, prevention, palliation, rehabilitation and so on. And fourth, the "ragged edge" of medical progress influences our ideas about what should be included as treatments and therapies in a basic level of health care.

In the United States today no issue is as widely discussed as health care and how to fund it. Debates about health care rationing, such as the Oregon plan, will continue in the near future. Restricting health care, however, threatens the integrity of health care professionals when it forces them to sacrifice their traditional commitments to particular patients for the sake of some overall societal good.

4. An Ethical Framework for Assessing Rationing Schemes

Rationing schemes that restrict the traditional patient-centered ethic of nursing and medicine threaten the integrity of health care professionals. For example, a nurse who owns a home health care agency believes her integrity is threatened because she must decide whether to restrict her services to those who can personally pay for nursing care. Her agency, established to serve an entire neighborhood, can no longer remain financially solvent if she continues to accept non-paying clients. Yet she believes she ought to offer services to the whole neighborhood otherwise certain poor neighbors would be institutionalized. Thus, overall health care costs would increase. Ought she to terminate services to particular clients?

The following ethical framework for examining rationing proposals addresses the question of how rationing health care can be reconciled with traditional professional commitments. The three elements of the framework are: fairness in allocation, contractualist justification and respect for persons.

Fairness in allocation requires that an unfortunate outcome be distinguished from one that is unfair. The following is a clinical example: If three persons were each equally qualified to receive a new liver, if the rules of the proposed allocation were just and scrupulously followed, and if, after the first two patients received their new livers the third potential recipient died before receiving his, the outcome for the third person would be unfortunate but not unfair. Not receiving a potentially helpful or even life-saving treatment is always unfortunate. But such a situation is not necessarily unfair if the system of allocation is more just than any other alternative.

A rationing plan that requires all to whom it applies to agree to accept its results (or would have so agreed if given the opportunity) is a good criterion of justness or fairness. Such a scheme would be like a well-run lottery in which a person could choose to buy a lottery ticket fully aware of all the rules and procedures. Assuming the lottery is legitimately managed, persons who purchased losing tickets could not claim to have been treated unfairly. That they lost would, of course, be unfortunate.

Contractualist justification can be seen in voluntary, cooperative prepaid health plans in which members jointly determine the extent of health care coverage. Paul T. Menzel presents a model in which members of such a plan considered whether to include coverage for liver transplantation:

After surveying the membership and a variety of discussions at different levels, the plan decided not to cover them [liver transplants]. At a cost of nearly \$300,000 per transplanted patient in first-year care and \$6,000 to \$7,000 per year per patient for follow-up costs, and with a first-year survival rate of 65 percent, in effect this is a decision that \$600,000 could be better spent on other things than five- to twenty-year additional life spans. The decision is publicized to the plan's current and prospective members and some other plans that cover this procedure are available in the community. Under these circumstances, who would really want to argue that the plan's doctors and nurses are violating their moral oath to patients if they subsequently cooperate with this decision?¹²

Basing the framework in part on the work of T.M. Scanlon, the contractualist criterion of moral justification requires health care rationing policies that cannot upon reflection be rejected by members who seek to make informed, unforced and prior general agreements. ¹³

Given society's view of the importance of equal opportunity, treating health care as a commodity available to the highest bidder is unacceptable.

A system of rules that cannot upon reflection be reasonably rejected is required for a sound health care policy that includes everyone in the group. Informed agreements presuppose that members of the group who set rationing policies for themselves understand their own circumstances; for example, the costs of health care, changes embedded in medical progress, and the group's costs for things other than health care. And finally, prior general agreement ensures that in the future, when specific individuals receive fewer medical services than they otherwise might, those individuals will continue to acknowledge their agreement with the rationing plan.

Contractualism, with its emphasis on informed, unforced prior agreement, supports development of a fair and workable system. But all of us, and nurses especially, must keep in mind persons who are most likely to be denied benefits under a pro-

posed rationing scheme and ask if we, given information about costs, the "ragged edge" of medical technology, and other costs of a particular group, would agree to the scheme.

Respect for persons is the third element of a framework for reviewing ethical rationing. Contractualist justification, based on respect for prior, informed, unforced agreement, can resolve the conflict between a health care professional's commitment to

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an individual patient and his or her role in withholding potentially beneficial care from the same patient. Contractualist justification requires that if rationing is carried out, the patient's prior, informed, unforced agreement to the plan would direct the health care professional to withhold certain types of care. According to Menzel, who has developed a contractualist conception of health care rationing:

If individual patients beforehand would have granted consent to the rationing policies and procedures in question (or more clearly yet, if they actually have consented to them), then the appeal of those policies and procedures will rest not merely on attachment to the morally controversial goal of aggregate welfare, "efficiency"; such policies will gain their moral force from respecting individual patients' own will.¹⁴

If employed in a health care plan in which members have agreed to limit specific treatments, a nurse must respect members' prior, informed, unforced agreements, a situation that may lead to withholding treatment that could potentially benefit a patient. In this situation a nurse ought not to be blamed for withholding care since she or he would be acting as an agent for the patient and, thus, respecting the patient's right to have made his own choices about health care coverage.

But nurses will, of course, care for patients who change their minds when faced with rare illnesses that possibly could be treated with expensive therapies. Before becoming sick these same individuals,

we assume, will or would have agreed that expensive treatment for the specific conditions be limited. In such cases their prior decisions ought to be honored in the same way that we respect a person's other rational choices. For example, certain individuals, overwhelmed with grief at the sudden loss of a loved one, may try to kill themselves. In such cases nurses express their respect for the person's prior rational desire to live rather than his or her present anguished impulse to die; thus, they rightly interfere with the suicide attempt.

Cost containment demands some restrictions on access to care, and fairness demands not discriminating against identifiable individuals. Therefore, restrictions on caring for specific individuals suffering from particular illnesses must be based on general policies that those individuals, we may reasonably assume, could not have reasonably rejected at some prior time.

We must, however, distinguish withholding efforts to cure patients from ceasing to care for them. Patients denied expensive, marginally effective curative treatments are nonetheless entitled to palliative care and emotional support that must be included as part of any ethically justified rationing system. Such care should be part of the basic minimum to which everyone has access. "At the center of caring," Callahan point out,

should be a commitment never to avert its eyes from, or wash its hands of, someone who is in pain or is suffering, who is disabled or incompetent, who is retarded or demented; that is the most fundamental demand made upon us. It is also the one commitment a health care system can almost always make to everyone, the one need that it can reasonably meet. Where the individual need for cure is infinite in its possibilities, the need for caring is much more finite—there is always something we can do for each other. The possibilities of caring are, in that respect, far more self-contained than the possibility of curing. That is why their absence is inexcusable. 15

In the present system the need for caring is too often sacrificed as the quest for cure consumes an ever-increasing part of the health care budget. One motivation for seeking a justifiable rationing policy, then, is to assure that resources for meeting the indispensable need for caring are adequate and fairly distributed.

Conclusion

No other health professionals know as much about, or are as skilled in, meeting the patient's

round-the-clock needs for physical, emotional and spiritual care as nurses. Given the central role of such caring in any rationing scheme and the fact that withholding expensive, marginally effective efforts to cure may require redoubled efforts at car-

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ing, nurses assume a correspondingly central role in debates over health care rationing. For example, the American Nurses Association's 1993 Public Policy Conference focused in part on what nurses are doing to shape health care reform. Through such efforts politically experienced nurses help others to gain skills in addressing health care issues at the federal, state and local level. Conceptions of nursing ethics that ignore this vital role are no longer adequate. The scope of nursing ethics must therefore expand from issues focused exclusively on individual patients and their families to questions about the justice of the health care system as a whole.

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