

***Medicine Without Limits:  
Limiting Medicine Ethically<sup>1</sup>***

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Which principles, concepts, approaches and ideas might help us to act ethically when we face tough decisions as institutions or governments as to what health care will and will not be provided? In exploring the ethics of limiting health care, as in many areas of ethics, we often focus on dramatic individual cases. Canada is typical in this regard. Front-page stories involving the lack of access to health care are reported in the Canadian press every day. In one story, a forty-five-year-old man with end-stage cystic fibrosis was called into hospital for a lung transplant, but no intensive care unit (ICU) bed could be found for him. The surgeon could not proceed because the patient could not be cared for post-operatively. The lungs available for transplantation to this desperately ill man were wasted. He could well die before other matching organs become available. The reason the ICU bed was not available was that a large number of hospital beds had been closed. In some cases, beds have been closed because of a shortage of nurses.

In contrast, two stories that described prominent Canadians who were politically well connected, who received heart transplants in 1993 and 1999, respectively, also raised our concerns, in these cases about the ethics of providing treatment to a certain person. Each man at the time of his surgery was the oldest person in Canada to have received a heart transplant. Questions were raised as to

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<sup>1</sup> Excerpts from *The Ethical Canary: Science, Society and the Human Spirit*

whether, in our purportedly totally egalitarian Canadian healthcare system, all patients are equal or some are more equal than others. Did these patients have access to heart transplantation mainly because they were prominent people and politically well connected or was it a coincidence that they shared these characteristics and, moreover, were both men? Let me be clear here. We have laws against discrimination on the basis of age, and access to health care is one of the most important contexts in which to apply these laws. But such laws must be used to protect everyone, not just selected people.

Of the many difficult issues discussed medical ethics, limiting medicine and doing so ethically are among the most complex for a wide variety of reasons. The decisions we would make about limiting medicine as a taxpayer in a socialized system or a person buying an insurance policy in a private system differ substantially from what we would want if we or our loved ones are ill and in need of health care. As well, we all personally identify with the need for health care and with people who require it, especially if it is denied to them. What's more, the decisions that must be made are diffuse, multiple, complex, interlinked, and frequently must be made concurrently at individual, institutional, governmental and societal levels. What we decide as a politician might be very different from what we would want for ourselves in health care—a reality that itself raises ethical issues that are discussed shortly.

It is easy, however, to focus on the rights and wrongs—the ethics—of individual stories about lack of access to health care, or unfair access. It is much more difficult to

place them in a larger context and to examine the ethics of the allocation of healthcare resources at the institutional, governmental or societal level. For instance, at the governmental level, what is the ethical responsibility to allocate resources to health care? And at the institutional level, what is the ethical responsibility for allocating resources within health care?

Trying to answer these questions is a daunting task. We have, however, no other option than to try to do so. The approach I propose has two main features: to use the lens of ethics, and to attempt to structure a framework of questions that will function as a conceptual tool we can use to help us make these decisions. In doing so, I first outline some of the features of the approach I have in mind. Then I use this approach to address selected aspects of the following questions: Who decides? On what basis? Using which procedures? And for which purposes?

### ***A framework of questions***

The framework of questions that I propose is complex, multidimensional, transdisciplinary, nuanced, and fluid rather than fixed. It must be structured to identify new questions that should be added and old ones that need to be deleted, and be able to easily accommodate such changes. Most importantly, it must be a carefully integrated whole. At present, the nature of decision-making in the healthcare system often seems like a cubist painting that presents disconnected pieces of a given reality. For instance, we might have the operating rooms and surgeons available, but there is a permanent shortage of anesthetists, which means that surgery cannot be performed. Or there is an expensive pain-relief treatment that would enable a patient to stay

out of hospital and avoid the cost to the system that a hospital admission involves, but the pharmacy budget has been exhausted and, therefore, the treatment is not available. The framework should help us to integrate our decision-making about health care as, indeed, we must do if we are to act ethically.

Such a framework of questions must be able to accommodate a wide range of ethical concerns, ranging from everyday ones—like access to basic treatment, the level of nursing care, or the length of waiting lists for elective treatment—to the most avant-garde, like access to expensive new diagnostic techniques or cancer treatments developed as a result of genetic research, or the issues raised by xenotransplantation. Many of these avant-garde issues can rightly be labelled “the costs of our success.” This description carries an important message in the context of concern over the cost of health care. Much as we would like to avoid our current “scarce healthcare resources” dilemmas, we face them precisely because we have been so successful in developing new medical technology, not because we have failed. Failure would have been very inexpensive financially, but unbearably expensive in pain, suffering and harm to our quality and length of life.

The framework of questions must also be able to accommodate analysis, especially ethical analysis, at different levels. For instance, at the institutional level it could be ethically acceptable for a hospital to decide, as a cost-saving move, not to install an ICU. But at the individual level it would not be ethical for a physician to deny such treatment to a patient who needs it, because the physician wanted to save the ICU resources for other

patients whom the physician regarded as having a better prognosis or quality of life.

Examining the ethics of the different levels necessarily opens up the question of whether we have obligations to provide some minimal level of health care to everyone in our world. Can we argue that there is a universal right to health care, and then accept that this right extends only to people living in affluent Western societies with socialized healthcare systems? Is "rights talk" the most appropriate language in which to explore our obligations to provide health care, especially to those who live outside our borders? Would "justice talk" or "ethics talk" be more appropriate?

As is so often true in doing ethics, the language we use in our dialogue about health care is not neutral. The ways in which allocation of resources are described in the community and societal-level debates can make a difference to the decisions we reach. In looking at obligations to those outside our borders, should we consider using a tripartite concept of human ethics, human rights and human responsibilities to articulate such obligations? Or would we achieve a more ethical, just and humane outcome if we placed more emphasis on practice than theory, and explored more fully and imaginatively practical ways of providing the most disadvantaged people in our world with basic health care? For instance, Dr. Solomon Benatar, a leading South African physician and ethicist, proposes that we should divert a small percentage of the money currently spent on military and militarism to provide some minimally adequate level of health care for people in the developing world.

The framework of questions must also be aimed at evolving a specific field of ethics to govern healthcare

institutions and systems. This field is called, alternatively, healthcare organizational ethics or healthcare institutional ethics and has emerged only recently. Its focus is to create ethical communities and an ethical climate within healthcare organizations. Kevin Wildes, an ethicist at the Kennedy Institute of Ethics at Georgetown University, proposes that institutions can possess both integrity and conscience—which means they can also lack them. Organizational ethics should be aimed at helping to articulate and develop the moral culture that will promote them.

We can contrast healthcare organizational ethics with clinical ethics, which has developed over the past thirty years and focuses largely on the individual healthcare professional-patient relationship and what is required to maintain the ethical integrity of this relationship. Our initial approach to healthcare organizational ethics was to write on the large screen the principles and approaches we had developed in this individual clinical context—for instance, the principle that the interests of the individual patient must come first. When we recognized the shortcomings of this approach, we often tried to deal with the larger issues through the application of business ethics. The difficulty with doing this is that, while health care has aspects of being a business, it is not just a business like any other, because while hospitals are in the business of caring, they also have a public mission and trust in relation to caring (even if they are privately owned hospitals). Therefore, unlike other businesses, to always give priority to efficiency, for example, in running a hospital, would be unethical when this priority conflicts

with what is needed to care properly, in the broad sense of this phrase, for patients.

In many ways, healthcare organizational ethics is a mixed system, which, as Jane Jacobs points out in her book *Systems of Survival*, is the most difficult system to govern ethically because the safeguards of one system do not work in the other and we can end up with no functioning checks and balances. We can see this, for instance, when we look at the nature of hospitals' obligations to patients. In acting as a healthcare provider to the patients, the hospital is governed by clinical ethics; in acting as a supplier to a customer, by business ethics. The problem is, as the American Joint Commission on Accreditation of Healthcare Organizations says, that the boundaries between these two roles of the hospital—between "clinical" ethics and "business" ethics and the different obligations to the patient they create—are not clear or are nonexistent. Moreover, the primary aims of the hospital in acting in one capacity or the other are not the same and can often conflict. When acting as a business, the hospital is concerned to guard against over-utilization or under-utilization of its resources. When the hospital is acting as a provider of health care in the clinical context, its primary aim must be the patient's well-being. We need institutional structures that can protect patients' welfare, but at the same time realize that goals such as efficiency and effectiveness are also ethically required. It will take deep thought (dare I say wisdom), integrity, courage, honesty and time to design and implement these structures. Many of us and many of our societies might have a rough ride—including ethically—before this process is completed.

We also encounter difficulties with developing organizational ethics because our basic presumptions are not neutral. Organizational ethics could ask us, for instance, to regard hospitals and other institutional healthcare providers—which could include governments that fund health care—as co-fiduciaries (co-trustees) for populations of patients. But what might be in the best interests of a population of patients can often not be in the best interests of an individual patient, and this is where the ethical conflict arises. Our current resolution of this conflict is to have individual healthcare professionals, especially physicians, act as fiduciaries for their patients. This role sometimes requires them to challenge the system on a particular patient's behalf, creating severe stress for both the physician and the system. One response to this dilemma is to argue that we need medicine that is appropriately—that is, ethically—economically disciplined: For instance, it is suggested that physicians need not tell their patients about more expensive treatments if the less expensive one is adequate but not as good as the other. But as ethicist Lawrence McCulloch has pointed out, being an economically disciplined fiduciary is an ethically unstable situation. The nature of being a fiduciary is to act in the utmost good faith, trust and confidence towards the other person. Physicians not telling their patients about better treatments clearly breaches these obligations. There is no point in creating a fiduciary obligation and then voiding it of any content. In fact to do so is more dangerous than not creating such an obligation.

We need institutional structures that ensure ethical behaviour, and we must eliminate those that do the opposite. In implementing organizational ethics, we must make certain

that our efforts do not detract from a feeling of ethical responsibility on the part of individuals. Organizational ethics must be in addition to, not in place of, individual ethical responsibility. Indeed, individual ethical responsibility is crucial to the practice of institutional ethics. Moreover, individuals must understand that they can play an important role in developing institutional ethics. An approach taken by the Quebec government is interesting in this regard. Instead of legislating a code of ethics for healthcare institutions, it legislated that each institution, after wide consultation with its staff, must draft and adopt its own code. This approach ensures that institutions take "ownership" of ethics within their milieu.

In establishing a framework of questions, we must also keep in mind that decisions about health care are never just about health care. In democratic Western societies, what we do and what we do not do in providing health care establishes important values and symbolism for society as a whole, particularly with respect to whether we espouse a fundamental value of caring for one another. Moreover, the ethical and legal tone of a society can best be judged by how it treats its weakest, neediest and most vulnerable members. In our Western societies, many of us experience such vulnerability only when we are among those who have, to use Susan Sontag's words in her book *Illness as Metaphor*, temporarily or permanently left the "kingdom of the well" to reside in the "kingdom of the sick." Health care—its presence or absence, its availability, and the conditions of its availability—can be regarded as one of the most important ethical canaries in the societal mineshaft. If the healthcare-system canary is sick, we need to be concerned

about the viability of our society, or at least the ethical and moral "air" on which its well-being depends.

### ***Uncertainty and courage...***

We need to learn to live comfortably with a certain degree of uncertainty in doing ethics. Nowhere is this more true than with respect to our decisions regarding healthcare institutions and systems. Politicians will need courage in deciding both what must be done and what must not, and—perhaps most difficultly—what will not be done although it could be, even though not doing it harms some people.

Courage requires being open and honest about the fact that these decisions are being taken and the reasons for them. It also requires that the decision-makers be responsible and accountable, if trust is to be maintained in both the decision-makers and the system they establish. Ultimately, and I have found most controversially, it requires, in my view, that in publicly funded healthcare systems, the decision-makers at the political or governmental level and their loved ones should choose to be subject to the same healthcare system as the people they represent. If we look at the healthcare system as a lifeboat—and that is what it is—then the politicians and their constituents must travel together. It is too easy to deny others access to certain treatment when you are confident that if you or your loved ones needed that treatment you would never personally face the same denial.

### ***Ethical limiting devices...***

Some important insights are emerging in relation to what is required in devising ethical limits on health care

in the context of medicine without limits. I will mention just a few of these "ethical limiting devices" here.

First, though it may seem obvious that public policy must be ethical, we are only very recently starting to articulate this requirement. It was in facing the fear and sometimes hysteria and stigmatization that erupted at the beginning of the HIV epidemic, and trying to formulate ethical public policy to govern issues raised by HIV infection and AIDS, that we became most aware of the need for ethics to guide both the formulation and application of public policy. This development might have been late in coming because governmental discretion and Crown immunity have meant that governmental agencies—which in many countries are the main decision-making bodies for the healthcare system—have not been subject to legal liability for their decisions. Consequently, ethical accountability was assumed to be, likewise, excluded. It is interesting to note that it was after the Supreme Court of Canada handed down groundbreaking judgments holding statutory authorities legally liable for some of their negligent decisions that consideration of the ethical obligations of bodies formulating public policy, which includes healthcare policy, started in Canada. For instance, while a statutory authority would most probably not be held legally liable for failing to have safety standards to govern the public water supply, it might be liable for failing to ensure that those standards it did have were properly applied by its inspectors when this failure resulted in death or injury to people who used that water supply.

Second, there is an emerging recognition that in some, or even many, situations, we may not be able to "do ethics" directly. Rather, we can set up conceptual spaces in which

it becomes more likely that the decisions taken will be ethical. For instance, if, in our main hospital, we have neither a pediatric intensive care unit nor a coronary intensive care unit and need, but cannot afford, both, using a conceptual space to make this decision might be the most ethical way to choose. We can imagine these spaces as metaphysical public squares in which all those who should be present are present and interacting with one another. It is from this interaction that decisions on healthcare policy should emerge. These spaces need to be inhabited by decision-makers who act morally, without conflict of interest, from a basis of earned trust and earned authority, and are accountable.

Third, increasingly, decision-making about health care involves different sectors. As well as the obvious players from the healthcare sector itself, government, business, industry and academia are all also now involved in healthcare decision-making. The ethical rules and bottom lines governing each of these sectors are not the same, a discrepancy that can lead to ethical conflict and ethical distress when we are prevented from doing what we believe is ethically required. The conflict can be between physicians and nurses or, as has become all too commonplace lately in the United States, between a physician who wants to provide a certain treatment for a patient and an insurance company that refuses to pay for it; or between researchers and a pharmaceutical company that challenges the researchers' results because they will be harmful to sales of its products.

In a complex and acrimonious case, physician-researcher Dr. Nancy Olivieri of the Hospital for Sick Children in Toronto became embroiled in a dispute with the

pharmaceutical company Apotex Inc., which was funding her research on a drug, L1 (deferiprone), which, among other indications, is given to children with thalassemia major (an inherited disorder of the oxygen-carrying red blood cells). Dr. Olivieri had signed a confidentiality agreement with the company, but based on her research findings she said that she felt morally and ethically obliged to breach it. She believed that her research showed a loss of effectiveness of the drug and adverse side effects and she wanted to warn of those dangers. She felt a particular responsibility, because her earlier research on deferiprone had promoted its use. The pharmaceutical company disagreed with her findings and responded with a statement that data from their clinical trials supported the safety and efficacy of the drug and that they were proceeding to obtain the approvals necessary for marketing it. Apotex threatened to take legal action against Dr. Olivieri if she published her findings. They did not do so, but the fallout from this dispute received intense public attention in Canada for a considerable period of time. It elicited a broad societal discussion of the ethics that must guide medical research carried out as a cooperative venture between hospitals, universities and industry, an increasingly common partnership.

Healthcare professionals who believe they are ethically required to act in a certain way, but are prevented from doing so by some person or body with authority over them, suffer not only ethical distress, but often also professional and financial harm. For instance, HMOs (health maintenance organizations which are medical insurance companies) may "de-select" a physician (that is, not renew a contract with a physician to provide services to people

insured with the HMO) if the physician's billing is above the norm.

Fourth, there is increasing concern in Western democracies that we have lost a sense of the common good and that no one is acting to protect the well-being of the community as a whole. Our decisions concerning health policy are important and rarely neutral in these respects. If they do not offer such protection, they are likely to harm the sense and reality of the common good and social cohesion. In some ways, we are never more alone than when we are ill, especially seriously ill. And yet in this situation we also need and can experience the most intimate and profound support of others. Most of us want this support to include whatever care and treatment might benefit us—indeed, we often feel entitled to it. And yet this care might be provided at the expense of others who also need health care. Can these conflicts be accommodated?

As a tentative suggestion, if we moved from using individualism as only a basis for rights and, as well, partnered these rights with correlative individual responsibilities, people might recognize responsibilities to the community and even engage in activism to fulfil them. Thus, individualism could, paradoxically, fuel a living sense of community. My friend and colleague Dr. Norbert Gilmore has been musing for some time on what he identifies as a lack of gratitude on the part of many of us—perhaps, sadly, a culture of ingratitude. If to our feeling of individual entitlement to health care we added one of gratitude that it is available, could this cause us to use health care differently? Might we feel obligations to maintain, protect or contribute to the healthcare system that we would not otherwise recognize? Could gratitude for

health care give us back a sense and reality of community? Might the loss of a sense of gratitude have contributed to a loss of a sense of community?

And fifth, we must accept that there is no magic solution, formula or bullet to solve the difficulties we face in the allocation of and access to health care. There are multiple considerations, concerns, players, issues, structures, decisions, values, norms, attitudes and beliefs—to name just some of the important elements that must be factored into any decision-making about health care. The answers to what is being called a crisis in health care in many industrialized Western countries with publicly funded healthcare systems are not just more money or a simple redesigning of the system. We must engage in real collective moral thinking and decision-making about the provision of health care. Beleaguered health ministers and other politicians are often tempted to turn just to statistics, including economic statistics, to “fix” the healthcare system. But this approach rarely allows for a careful, in-depth, broad exploration of the values that should govern health policy decision-making.

If, as is being said, we are moving from materialism—where economic values predominate—to post-materialism—where other values are at least as important as economic ones—this new climate will affect both the content and process of our decision-making about health care. It will certainly mean that economic statistics are not, alone, an ethical basis on which to decide on health policy and healthcare funding. And yet some of our publicly funded healthcare systems—and, of course, privately funded ones—seem to have moved instead to a sole dependence on economics. We must go back to the ethical drawing board in this regard.

I believe that, at present, decision-making about health care is in the "chaos" or second phase of the triad of phases that we pass through in evolving new knowledge. Until the late 1960s, we were in the "true simplicity" phase. At that time, decision-making was not difficult, mainly because the health care we had developed was limited compared with what we can offer now; because we were not as sensitive as we are today to the ethical obligation to provide everyone in our society with reasonable access to health care; and because the power of health care to do harm was as limited as its power to do good. Because all these factors and others changed, we have moved with increasing momentum into a chaos phase with respect to health policy decision-making, and we are still experiencing that phase. We know and can do much more; we recognize obligations to provide access to health care; and we are aware of the power of health care for good and, sometimes, harm. But we have not yet structured our knowledge in a way that allows us to feel reasonably certain we are "doing the right thing." When we have structured this chaos, we will move to "apparent simplicity." This last stage can look very like the first one, and the decisions we make may be the same as or very similar to those that we made at the true simplicity stage. This decision-making is different, however, because unlike decisions at the true simplicity stage, these decisions are based on in-depth knowledge. We could also regard this progression in the sophistication of our decision-making as an example of our using reason at the third or apparent simplicity stage, to verify the intuitive responses we had at the first or true simplicity stage.

### ***Four questions...***

Let's now examine the four questions, the responses to which are major determinants of the system we will find waiting for us when we need health care: Who decides? On what basis? Using which procedures? And for which purposes?

### ***Who decides?***

Whether you or members of your family receive certain types of health care depends mainly on your physician. The final allocation of nearly 80 percent of all healthcare resources is made by physicians. This allocation mechanism is sometimes described as "de facto gate-keeping" and physicians necessarily have to undertake it—it is an intrinsic element of the practice of medicine. Because the physician has a primary obligation of personal care to the patient, the physician must act without conflict of interest and in the patient's sole interests in undertaking de facto gate-keeping. The interests of others—other patients, family or society—are secondary. De facto gate-keeping by physicians can be compared to "positive gate-keeping"—in undertaking this action the physician benefits personally from allocating resources to patients—and "negative gate-keeping"—in which the physician benefits personally from restricting patients' access to resources. Some commentators believe that the latter two forms of gate-keeping are inherently unethical. Certainly, if they are allowed, great care needs to be taken to ensure that physicians engaging in them act ethically.

Unethical incentives for physicians can range from financial or other benefits for using certain companies' products, to being a part-owner of a diagnostic laboratory to which patients are referred, to health insurance

companies paying physicians a bonus for denying patients' access to necessary medical treatment. Giving physicians financial rewards for refusing patients' access to treatment matters, especially when that treatment might be life-prolonging or even life-saving as could be true of some treatments for diseases such as cancer. Physicians employed by some HMOs in the United States have given evidence to hearings investigating the healthcare insurance industry that they received bonuses for rejecting other physicians' applications for approval of certain treatments for patients. Some of these decisions might have been unethical. For instance, a physician whose terms of employment included such a bonus scheme gave evidence that she deeply regretted rejecting a certain treatment for a woman who was suffering from breast cancer—in fact, she said the case haunted her—because she believed the woman should have been given it. Let's think about the ethics of this: It is one matter to reject a treatment because it is inappropriate—or even, perhaps, because it is just too expensive. It is quite another matter to reward a physician for issuing such a rejection.

Physicians can also be placed in conflict of interest by the policies governing the allocation of resources adopted by the healthcare institutions in which they work or by the healthcare system or insurance company that reimburses them for their services. To say the least, healthcare policy-makers and institutions such as hospitals must take care not to place physicians who must allocate resources in unethical situations and cause them to face unethical choices. In short, the systems that institutions establish must themselves be ethical. Ethical difficulties can arise at the interface where the physician's primary

obligations of personal care to the patient—for instance, to obtain the patient's informed consent to treatment—meet the reality of healthcare policy. For example, physicians find themselves in difficult ethical situations when they know that the patient requires treatment as soon as possible, but the waiting lists will result in serious delay that threaten the patient's life or health. Or, physicians can face ethical difficulties when a hospital or healthcare system limits the range of treatments a physician can offer to a patient, because these limitations can mean the physician is acting unethically.

For instance, if a cardiac surgeon is told that she may implant a maximum of only ten intracardiac assist devices per year, when the surgeon and the hospital know that, on average, at least fifty patients will need and could benefit from this potentially life-saving treatment (the device is a defibrillator that is automatically activated if the person suffers a cardiac arrest), the surgeon faces horrible choices in using the ten devices that are available. Ethically, the only acceptable way to allocate them is on the "first-come, first-served" basis for those who need and could benefit from them. Some people propose that there is another ethical alternative, a lottery. But most of us react with shock to this proposition, a response that may reflect a moral intuition that there is something unacceptable about it. Imagine actually pulling a number out of a hat in the presence of a person who needed such a device. The person is probably at increased risk of cardiac arrest on the spot. How we will allocate such devices is a current ethical dilemma in Canada. Some estimates are that if everyone in the country who could benefit from such a device were given it, the cost could be as high as 4 percent of the total

Canadian healthcare budget—and that is the cost for only one item of the new technology.

Decision-makers about health care must also “think outside the box” in assessing how, ethically, to limit healthcare costs. For instance, acting ethically by respecting people’s autonomy and right to decide for themselves which treatments they want or do not want can reduce costs: Many people refuse expensive, invasive, minimally life-prolonging treatments. Sometimes lateral thinking about cost-saving is also productive. For instance, helping people to deal with their fear of death and offering them palliative care can give patients a wider range of choices about care and treatment at the end of their lives. Some of their choices could also be cost-saving—but even if they are not or cost more than other options, ethically we might still be obliged to offer them. So saving healthcare resources and augmenting ethics are not always or necessarily antithetical; rather, the contrary can be true.

In the same vein, those making decisions about health care must be careful not to assess its costs within too narrow a framework. Some of our healthcare cost accounting may be warped because we adopt a “silo mentality”—we artificially divide costs into different streams (hospital care, home care or pharmaceuticals) and fail to recognize that small or moderate extra spending in one stream can save major costs in another. This mentality gives skewed results, which can, in turn, lead to unethical decisions, especially with respect to the allocation of resources. For instance, better pain-relief treatment can mean that a patient does not need hospitalization and can thereby save hospital costs. But our reluctance to spend money on very expensive pain-relief treatment may blind us to the greater overall

saving that it could produce, quite apart from the fact that we would be doing the right thing ethically by making such treatment available. To give healthcare decision-makers the benefit of the doubt, they might not be aware of the suffering they cause with some of their cost-saving strategies. The alternative explanation is that they are acting grossly unethically in making certain cost-saving decisions. For instance, leaving people on waiting lists for treatments does not ultimately save the cost of the treatments these people need—unless they die while waiting. Surely, this could not be an anticipated outcome? Indeed, such patients' needs for stop-gap measures often increase the overall cost.

We need to see the big picture. We must apply the calculus of how much reduction in suffering each healthcare dollar we spend achieves and how much suffering each healthcare dollar we refuse to make available inflicts. But at the same time we must take great care not to use this calculus unethically—for instance, by wrongfully using our perception that the amount of reduction in suffering delivered does not merit the cost of the treatment in question. These are difficult calculations and are values-based. Moreover, how do we balance the suffering of one individual with that of a large group? Should we give priority to relieving the great suffering of one person over relieving the lesser suffering of many? Old questions, but ones that must still be addressed in the context of contemporary health care. Suffering can also be very hard to assess. Often it is not open to being measured quantitatively; rather it requires qualitative assessment, and healthcare administrators and policy-makers can be suspicious of qualitative assessment. This suspicious

attitude is a mistake and can lead to unethical decisions in relation to both the provision of health care and the formation of health policy in that these decisions fail to give proper weight to fulfilling ethical obligations to relieve suffering. Macro- and meso-level decision-making about health care and policy is, indeed, an area in which it can be easy to say what is required from an ethical stance, but very difficult to translate it into concrete terms.

The ethical need to involve the public in health policy decision-making in general has been brought to the fore by new technologies, such as xenotransplantation and human cloning, that pose risks to everyone, whether at the physical or metaphysical level. I believe direct public consultation is likely to become increasingly common. It will be necessary as a political reality—if not for any other better reason. Perhaps the most serious danger in such consultations is that it will be only a façade. The public is already cynical about how decisions affecting it are made, especially those related to new technologies, as recent controversy over genetically modified crops and food has shown. To undertake public consultation that was anything other than open, honest, genuine and substantive would do harm to public trust, not only in the immediate situation to which it was relevant, but also much more widely. Such harm is of the most serious concern because ultimately the survival of our kind of society and democracy itself depends on public trust. We must therefore be fully conscious, at all times, of our obligations to act in such ways that public trust is honoured and reinforced.

Acting ethically at the level of societal decision-making also requires that macro-level decision-makers be held accountable for the decisions they make. The greatest

source of mistrust, fear and anger on the part of the public occurs when they encounter a faceless bureaucracy and politicians who deny responsibility. Our systems have not always functioned well in the past in relation to such accountability, as the tragedies surrounding the transmission of HIV and hepatitis C through the blood system have shown.

This same context also provided, however, a remarkable example of a Canadian politician standing up to be accountable. The Government of Canada set up a royal commission (the Commission of Inquiry on the Blood System in Canada, the Krever Commission) in 1993, to investigate how the Canadian blood-supply system became contaminated with HIV and hepatitis C. The Honourable Monique Bégin was Minister of Health for Canada during part of the time these tragic events occurred. A lawsuit was launched seeking an injunction to prevent the commission from specifically naming certain people in its report as potential wrongdoers. These were all people who had made decisions or given advice about the blood-supply system at relevant times, and Mme. Bégin was one of these people. The court granted all the political decision-makers, including Mme. Bégin, immunity from being named by the commission. Mme. Bégin waived her immunity—no other politician or bureaucrat who had likewise been granted immunity took such a stance publicly. She made this decision because she believed passionately that ethically she must take responsibility. But she was very unsure what might happen as a result of doing so. As she left my office having made her decision, her parting words were "Wish me bon courage." The public's response to her act was overwhelming. Hundreds of people telephoned, faxed or wrote letters, all more or less along the same lines: "Thank

God, that at last a politician has said, 'I will be held accountable'." There is an important and powerful lesson here.

***On what basis should we decide?***

The topic of what should be the basis of our decision-making about health care is enormous. It is not possible, here, to do more than identify some of the considerations that must be addressed. What one considers to be ethical and unethical in decision-making about health policy and health care can vary. For instance, someone deciding on the allocation of healthcare resources on the basis of a virtues-ethics approach (that is, deciding on the basis of acting morally or virtuously in making the decision) might reach a different decision than someone who valued utility foremost. The former might give priority in access to health care to the least privileged and most vulnerable people—homeless people, for example. The latter could base their decision on achieving the greatest health benefits for the largest number of people, who might be more privileged young adults.

The interaction of law, ethics and guidelines also matters in decision-making about access to health care and healthcare policy. There is a difference between assessing the acceptability of a decision about health care on the basis of whether it is, first, legal and, second, ethical, as compared with the converse. It is especially important in this area for ethics to inform law and for law not to limit ethics. Working from ethics to law makes this preferred result much more likely than working from law to ethics. We

can see this difference by asking, for example, whether people have a right to have access to adequate pain-relief treatment. Ethically, the answer is clear: They do. Some healthcare institutions have been more concerned, however, to ensure that pain-relief drugs are not misused (because the institutions could be legally liable if the medications were misused) than to ensure that patients have access to all necessary pain-relief treatment. Consequently, they have set up systems that make it difficult to provide patients with adequate pain-relief treatment. This is a case of law informing ethics. We must bring the law into line with ethics in such situations, which is more likely to occur if we start our analysis of any given situation from ethics.

Internal hospital policies are also used as a basis for decision-making about health care. Guidelines that articulate an institutional policy that requires, for example, that "do not resuscitate" (DNR) orders are to be placed on all patients raise ethical problems. Patients have a right to individualized personal care. To treat them as a group to which a blanket decision may be applied—especially one concerning life-saving treatments—is unethical and could often, as well, result in legal liability. Sometimes, in the past, these types of decisions have been taken on the basis of age—for instance, no one over sixty-five years of age will be given haemodialysis for terminal kidney failure. These decisions are unethical and also breach the law against discrimination on the basis of age. Care must be taken that such decisions are not still being taken, but under a medical cloak—it is common to hear healthcare professionals explain that a person would not benefit from a certain treatment because he is too old. Sometimes this judgment is correct, but sometimes it is latent, age-based

discrimination. Guidelines used as a code for a series of decisions that are not made explicit also raise ethical concerns. For example, in some institutions, a DNR order does not simply mean that the people to whom such an order applies will not be given cardiopulmonary resuscitation should they have a cardiac arrest. Rather, it is a code for the withdrawal of all life-support treatment, including antibiotics or other therapies.

The basic presumptions on which we base our healthcare decision-making can also have an effect on our decisions. In situations of equal doubt as to whether we should provide certain health care, the basic presumption will govern and, therefore, will determine the outcome. If the basic presumption is one of access, it will be provided in situations of equal doubt. If the presumption is against access, the opposite will be true.

There are four basic presumptions. When they are applied to access to health care, let us say to the intracardiac assist device we have already considered, these become no access—it is too expensive; no access except on certain conditions—you must first try all less expensive treatments, such as drug therapy, and have these fail before access is given; access but limited on certain conditions—the treatment will be given but not to people with (to use a hypothetical example because there is no research data on this yet) end-stage congestive cardiac failure, because it has been shown to be minimally life-prolonging or ineffective in such cases; and access freely given. In general, the presumption that should, I believe, apply is access to all medically necessary health care, but limited if certain carefully defined conditions are fulfilled. The people denying access to health care should have the burden

of proof; they must show they are justified in withholding it.

One question being asked is whether health care is a special "public good" with priority over other public goods such as education, welfare or housing. One could argue that it is a special public good on the basis of justice; on the basis that respect for persons and their human dignity requires the provision of health care to them; and on the basis that a right to health care is essential to the enjoyment of all other rights because one cannot exercise them if one is sick. In practice, health care claims can take priority over other comparable claims, through the often innovative use of law. Relevant law, ranging from public international, human rights and humanitarian law, to constitutional and private law—such as tort and contract liability—can be used to establish and implement a right to health care. Although such cases usually directly involve only one individual, they can set precedents that affect everyone as some recent Canadian cases have demonstrated.

At a policy level, there are arguments both for and against establishing a right to health care. Those who support such a right worry about people not having adequate access to health care and seek to ensure that their healthcare needs—if not all their healthcare desires—are fulfilled. Those who oppose such a right worry about the costs of universal access. As is often the case, there needs to be a careful balance between these two arguments: We need adequate access and we need adequate, ethically acceptable, controls on access.

Another way to assess the amount of health care to which people should ethically be given access is to work from a "mutual responsibilities" concept. If we belong to a

family, community or society, we have responsibilities to the others who also belong and they have responsibilities to us—we are inter-dependent. In some cases this approach will lead to the same conclusion as a “rights-based” analysis, but in other cases it might not do so. For instance, a state that has encouraged its citizens to rely on it to provide health care in return for their paying taxes to support this service may have obligations to citizens who have relied to their detriment on the state’s undertaking in this respect. Let us imagine, for instance, that the state decides to privatize its healthcare system. People who have contributed to the state healthcare system throughout their lives through their taxes, and who are now old and ill and consequently unable to buy private insurance, would in my view have a strong ethical claim against the state for the provision of all necessary health care. Whether the state would have legal obligations to these people under a mutual-responsibilities approach is not clear. Such obligations would be more likely to exist under a rights-based approach to access to health care.

It also merits noting that our view of the nature and content of mutual responsibilities with respect to the provision of health care will differ markedly depending on how we view the nature of a profession and professionals’ obligations to the community. If a profession is seen largely as a free-enterprise business venture, it will entail very different responsibilities than it will if it is seen as a trust given to healthcare professionals by the community to be used on behalf of the community for the good of each of its members. While some countries adopt one or other of these approaches, in Canada we have a mixed system that can be a basis for confusion and ethical difficulties.

Sometimes when we expect healthcare professionals to act as the holders of our trust, they act on a "business" basis. This is seen most starkly when healthcare professionals take industrial action—especially strike—in order to improve their working conditions. We are shocked at their doing this because we experience their actions as a profound breach of one of our most important areas of trust. In contrast, the healthcare professionals who are prohibited from striking regard themselves as being penalized in comparison with other kinds of workers who can use such tactics to further their claims. Sometimes the situation is reversed. Healthcare professionals, in particular physicians, claim privileges of professional autonomy and self-regulation on the basis that they are a trusted profession, when the public, as is currently happening in Ontario, seeks to have greater input into the regulation of the profession and individual practitioners, and a greater say in their control.

Yet another way to approach decisions about health care, especially healthcare policy, is to look at the values that inform such decisions. Australian medical law professor Philip Bates and his colleagues have suggested that we can divide these values into a series of six clusters: paternalistic; maternalistic; liberty; social conscience/fairness/equity; social efficiency/managerialist/economic rationalist; and "rule of law"/democratic. Which of these clusters we adopt, and which we give priority to when there is conflict between them, will differ according to our own values, beliefs, professional background and experience. Our decisions concerning health care will vary depending upon which value cluster is given priority. Often, we can obtain insights

into the acceptability of our decision-making about health care, especially its ethical acceptability, by identifying the cluster of values that is given priority in making any given decision. For instance, a decision that has a harmful outcome for some people may be ethically acceptable if this decision is taken on the basis of social conscience, fairness and equity. The same decision may be unethical, however, if taken on the basis of social efficiency and managerialist and economic rationalist aims. A decision to spend healthcare dollars on socio-economically disadvantaged pregnant women at high risk for giving birth to premature babies, which means that we cannot afford a state-of-the-art intensive care nursery, may be ethically acceptable. But a decision simply to cut funding for intensive care nurseries in order to reduce the government's budget deficit, no matter the need for such nurseries or the harm done, would not be ethical.

We react more powerfully to some failures to uphold values than to others, not because of a difference in the seriousness of some failures as compared with others, but because of differences in the way in which these occur or the features of the decision-making that gave rise to them. For instance, we are often more appalled by a lack of adequate medical facilities for a very sick newborn child than we are by the avoidable damage that is suffered by a premature newborn baby whose mother did not receive adequate care during her pregnancy. Overt, direct threats to important values that cause obvious harms are much less ethically tolerated than are latent, indirect threats caused by difficult-to-identify decision-makers to difficult-to-identify victims. This reality can be unethically manipulated in decision-making about health care, especially

at the institutional or governmental level. We fund the intensive neonatal nursery and make a large public fuss about it, which overshadows the other less obvious decisions not to provide health care that people need. Diffusing the decision-making and the responsibility for it, making it difficult to find out who decided and who should have decided, and failing to keep adequate records or to monitor the harms that result from decisions about health care—these are all ways in which decision-making can be unethically manipulated.

***Which processes should be used?***

The process used for healthcare decision-making can have a major effect on the decisions that are made. Ethics committees are a relatively recent but increasingly used mechanism for decision-making about health care at the individual, institutional and societal levels. One important task for ethics committees in the future will be to help to develop the area of organizational or institutional ethics. In doing so, they should have a strong emphasis on “preventive ethics”—that is, what is needed to establish ethically sensitive institutional structures and systems and to identify situations that present risks of unethical conduct, especially in formulating and implementing health policy that governs the allocation of resources and access to health care.

But ethics committees are not without dangers. One danger lies in the choice of members. Some people assume that doing ethics is nothing more than a matter of good personal conscience and, as a consequence, some ethics committees operate without any member who has training in ethical analysis or adequate access to professional

consultation on the matter. I have had this fact brought home to me in reviewing research projects the funding for which has been refused on ethical grounds, or reviewing an ethics committee's approval of a certain project that raises serious ethical concerns. The projects were being carried out at major Canadian universities or teaching hospitals.

In one case the ethical approval had been given by a committee that had no member with ethical expertise. The principal researcher on the project recognized that the research raised serious ethical concerns and was nervous about relying on the approval given; as she phrased it, she "didn't want to be hung out to dry" if, when knowledge of the research became public, there were concerns about its ethical acceptability. The project was sent to me when she asked the funding agency to obtain a "second opinion" on its ethics. Twelve months later, we are still working on addressing the ethical issues that this important research raises, so that it can go forward.

In another case, a well-known ethicist was listed as a member of an ethics committee that had approved a research project involving children. This project needed, as well, the approval of the research ethics committee of the granting agency funding the research. I chaired this second committee. We believed the research raised serious ethical concerns and agreed I should contact the ethicist member of the first committee. When I did so, she said she was a member of that committee but had never seen this project. We had been sent a list of the members of the institution's ethics committee, not those members who had actually reviewed this research protocol.

In yet another case, the principal researcher had acted as a member of the ethics committee and as its expert

adviser on the risks involved in his own research project on premature newborn babies. The committee had approved the research as ethical, but the funding agency rejected this finding simply on the basis that the research, as described in the proposal, was on its face unethical. The funding agency did not know about the conflict of interest problem. The researcher appealed the rejection, arguing that funding agencies had no right to second-guess an ethics committee as to what was and was not ethical. It was as part of the appeal process that this conflict came to light. The researcher's appeal was dismissed.

I do not want to leave the impression that ethics committees are not effective or act unethically. They are effective and none, in my experience, act in bad faith. But sometimes they can best be described as struggling to do a good job because they do not necessarily or always have the ethical knowledge or expertise that they need. In large part, it is because applied ethics is a new field in which Canadian students, like others around the world, are only now specializing.

There is also another danger in having safeguards, such as ethics committees, if they are not effective. If safeguards are present, most people are much less concerned about a situation than they would otherwise be. We are better off not having any safeguards than we are with ones that do not function effectively and provide a false sense of security. Care also needs to be taken that there is not an abnegation of personal responsibility on the part of the members of an ethics committee. We can feel safer in groups than when we are a lone decision-maker. Committees can sometimes reach decisions that no one member acting alone would ever take.

An ethical process for decision-making about health care should include mechanisms that allow patients or institutions to appeal decisions they see as harmful to themselves or others to whom they owe obligations. For example, if an insurance company refuses to pay for an experimental treatment for an insured patient, there should be a mechanism for appeal to an impartial body of decision-makers who can review and, where appropriate, reverse the decision. Similarly, people suffering from fatal illnesses for which no standard treatment is available need to have mechanisms in place for the compassionate release of treatments that are currently being tested in clinical research trials. For instance, under the Canadian Food and Drugs Act, experimental drugs can be made available on an individual ad hoc basis when they are a person's only hope for treatment of a life-threatening condition, such as AIDS or cancer.

Some decision-making about health care ends up in the courts, whether as a result of claims to a right to health care or as medical malpractice litigation. These cases, often have a powerful impact on the access of large numbers of people to health care or the standard of care they receive. In the future, advocacy groups will likely use the courts either to make governments deliver health care or to hold them liable for failing to have done so. As mentioned already, while the Supreme Court of Canada has recognized that statutory bodies have legal immunity for their discretionary decisions, it has held them legally liable for their negligent operational decisions. These cases arose outside the healthcare context, but similar actions will likely arise in the future in that context. For example, while the government's allocation of funds to health care is

discretionary and, therefore, could not be legally attacked, the decisions that a board, which is responsible to provide certain services, makes about the use of the funds it receives are more likely to be operational and, therefore, open to challenge and potential liability if a decision is negligently made.

Healthcare advocacy groups are becoming an increasingly forceful voice in decision-making about health care. They have influenced the allocation of healthcare resources and, to a large extent, have improved the access to health care of people whose interests they represent. The efforts, starting in the early 1980s, of those advocating for medical research on HIV infection and AIDS and health care for people with AIDS provided a model that others have now followed. Advocates for women with breast cancer used the "AIDS advocates" as a model and went on to point out the large discrepancies between the amount of money spent on research on AIDS as compared to that on breast cancer, although breast cancer was also a potentially fatal illness that affected a greater proportion of the population (who were mainly women) than did AIDS. In doing this, they were not proposing that the funding for AIDS research should be reduced, but that resources for breast cancer research should be increased. They have been successful in raising awareness of breast cancer and increasing funding for research and treatment. Advocacy groups do much good, but we must remember that not all those people or diseases that have an ethical claim on healthcare resources have a group advocating for them and these people's claims and needs can be overlooked. While advocacy groups have an important role, competition between these special interest groups for a share of the necessarily limited healthcare pie may not be

the most equitable way, overall, to distribute healthcare resources.

Macro-level decision-making about health care is undertaken as part of the bureaucratic and political process and is therefore likely to be driven by social efficiency, managerialist, economic rationalist values. Pursuant to these values, bureaucrats often want to implement quality-control mechanisms. But while there is a valid role for quality control, we must ensure that it is used ethically. One problem is that although quality is sometimes treated as an objective criterion, in fact it is often values-based, leading to questions of whose values should predominate when there is conflict. Moreover, some of the most important aspects of health care, such as healthcare professionals' empathy and compassion for patients, may not be readily amenable to a quality-control assessment. We must be careful in deciding what elements or characteristics of a healthcare system should be assessed for quality. As physician and ethicist Howard Brody says, sometimes the measurable drives out the important.

Mark Schacter, a journalist, points out in an article in the National Post titled "Health-care report cards" that health care improves our lives in ways that cannot be measured in dollars and cents, and that health care does not have clear simple goals that can be assessed. He asks what factors should be measured: the overall health of a country's residents? The geographic distribution of facilities and personnel? The time you wait to be treated in an emergency room to see a specialist or have surgery? The efficiency of hospital bed management? The availability of advanced equipment? The frequency of malpractice? Courteous treatment? He says:

Each measure reflects an aspect of what we demand from the system. Some are about quality of care, some about fairness, some about efficiency and some about effectiveness. Danger lies in a measurement system that unduly emphasises one to the detriment of others. Imagine a system where hospitals are judged on the basis of rapid turnover of hospital beds. Likely outcome? Too many patients sent home too early. A mistaken view of efficiency tramples quality and effectiveness. Rather, he says, we need "a good mix of efficiency, effectiveness, equity and quality." But even then the media and politicians could use reporting on health care to seek scapegoats. Therefore, we must develop a healthcare reporting system "wisely and use it responsibly."

As Schacter outlines, a wise healthcare reporting system will require that we make changes when needed and admit our mistakes; it will also require a broad involvement, especially of the public; a mixture of measures covering efficiency, effectiveness, equity and quality; assessment of some final outcomes (for example, healthier citizens), but acknowledgement that some outcomes are beyond government control; that we learn from failure rather than stigmatizing it; and that we stop looking for someone to blame except those who fail to learn from failure. This is, indeed, wise advice.

### ***For what purpose?***

Our purpose in engaging in decision-making about health care can also affect the ethical acceptability of the decisions we make. For example, to subject a person to

compulsory treatment for infectious disease in order to protect public health is ethically acceptable under certain conditions and if this is the only reasonable way to prevent the spread of a serious infectious disease. Compulsory immunization of children can be justified on the same basis. An analogous question is: To what extent are we ethically justified in rejecting some individuals' claims to health care in order to protect the viability of the healthcare system as a whole? Does this reason for rejecting these claims—that is, our purpose in doing so—mean that we are ethically justified in doing so, but if this purpose were absent, so would the ethical justification?

One of the most contentious decisions in health care at the macro level is to allocate resources with an obvious aim of gaining political advantage. All such decisions should be assessed for ethical acceptability, and some will be found to be unethical. We cannot, however, lay all of the blame for these unethical decisions at the feet of the politicians involved. We, as the public, must also act ethically by not re-electing politicians whose actions are unethical, especially in relation to their decisions concerning health care. We should ask who is responsible for unethical responses on the part of the politicians, and we should recognize that sometimes, in part, we the public are.

### **Conclusion**

It has been said that psychoanalysis is an impossible profession and sometimes it is more difficult than others. Likewise, formulating and applying health policy and designing and running a healthcare system—especially ethically—is an impossible task and sometimes it is more difficult than others.

In his book *How to Do the Impossible*, Andy Nulman, a Montreal entrepreneur, lists his rules: Have dreams and visions about what you want to do; believe that it is possible to achieve them; live in tomorrow, but not for tomorrow; and regard your failures as learning experiences, not defeats. This is probably good advice to apply in our efforts to maintain our healthcare systems.

I have merely touched on the vast and complex range of ethical issues that our healthcare systems are confronting in trying to balance fulfilling individual needs and maintaining community confidence and protecting the common good. You may feel, rightly, that I have presented only problems, not answers. In my view, however, asking as many as possible of the right questions about our health policy and healthcare system is likely to be more important than the finding of any one answer—or even many answers. Questioning necessarily involves uncertainty, and to return to a theme I have mentioned before, living with uncertainty—certainly consciously choosing to do so—requires courage. Because science and technology continue to advance at astonishing speed, we will all—whether as patients, families, healthcare professionals, healthcare administrators, government bureaucrats or politicians—need courage and compassion and wisdom in full measure in ethically limiting medicine without limits.

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