Dollars, Death and DNA – Ethical Challenges at the Frontiers of Health Care
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Peter A. Singer, MD, MPH, FRCPC
Sun Life Chair in Bioethics and Director, University of Toronto Joint Centre for Bioethics

I first became interested in bioethics in the early 1980s. At that time, I was training as a doctor. I became interested in why some patients in the hospital received resuscitation when their heart stopped and others did not. To my surprise, I discovered that the main factor driving this decision was the customary practice of the doctor, and not the wishes of the patient or family. The decision about resuscitation was written in pencil on the nursing notes, and erased after the patient died. This was wrong.

I thought there was probably a better way to do this. The irony was that we could spend hours talking about 15 obscure causes of a low serum potassium or sodium level, but we didn't seem to consider ethical issues like resuscitation very systematically.

As this vignette illustrates, bioethics issues can deeply touch the lives of Canadians. These are not just theoretical or abstract problems. They are amenable to solutions. For instance, resuscitation decisions are now guided not by the customary practice of the doctor, but by the wishes of the patient and family.

Bioethics is a field of scholarship devoted to the study of ethical issues of high social relevance in health care. It brings together many different perspectives -- law, medicine, philosophy, nursing, religious studies, social sciences, and other disciplines. Bioethics is capturing the interest and support of concerned institutions, like the seven University of Toronto teaching hospitals participating in the Joint Centre for Bioethics; individuals, like Dr. Miller Alloway; and corporations, like Sun Life, represented here by Mr. Donald Stewart, Dr. Ross Mackenzie, Dr. Bruce Rowat, and their colleagues.

This afternoon, my purpose is to give you a sense of this relatively new field of bioethics by considering with you three specific issues – dollars, death, and DNA.

Dollars

We are in a federal election campaign. Health care emerged as one of the key issues (at least before it was submerged by national unity). It is well known that during the past few years the federal government has cut billions of dollars from transfer payments to the provinces, and that many provinces have restructured their hospital systems in an attempt to achieve savings.

These events have drawn attention to the issue of resource allocation in health care. Although resource allocation is usually thought of in a climate of diminishing or flat health care resources (which has been the situation in the past few years), it is just as important when resources are increasing (as they will likely do, modestly, in the coming few years).

If a health care facility received another $10 million tomorrow, it would still have to decide how to allocate the new money fairly.

There will never be enough money to provide all the health care we could possibly provide. This is because of the problem of marginally effective therapy. There is always another treatment to try that may provide a tiny increased chance, but at an exorbitant price relative to the benefit.

So, the key question becomes, How should we distribute society's health care resources fairly?

This is a problem in distributive justice. Unfortunately, although there are different philosophical theories of justice, there is no overarching theory that provides a solution.

Consider some of the unsolved philosophical problems of resource allocation (I have drawn these from the work of philosopher Daniel Callahan).

How much should we favor producing the best outcome with our limited resources? For example, two patients need a heart transplant. One will live 20 years and the other 40 years. Which one should receive it?

When should we allow an aggregation of modest benefits to larger numbers of people to outweigh more significant benefits to fewer people? An example of this problem arose in Oregon, where the state undertook an explicit exercise in resource allocation, when tooth capping was prioritized over surgery for acute appendicitis for public funding.

When resources are limited, should we fund a program where there is high quality evidence of a small benefit, or one where there is lower quality evidence of a large benefit?

How much priority should we give to treating the sickest or most disabled patients? This problem has also been dubbed the "Coby Howard factor" after the 7-year old boy who died of acute lymphocytic leukemia while his mother was raising funds for a bone marrow transplant for which he was ineligible under Medicaid. It is also called "rule of rescue" -- people's perceived duty to save endangered life whenever possible.

When must we rely on fair democratic process as the only way to determine what constitutes a fair rationing policy? An example is the prioritization of vasectomy above hip replacement, based on community values, in the Oregon plan. Different groups in society have different interests and values, and political processes are important in resource allocation decision making. Any resource allocation scheme needs to take account of this pluralism of values.

To address the problem of health care resource allocation, we need a set of guiding principles. The principles would need to take account of these unsolved problems in resource allocation, as well as work in practice.

Surprisingly, we do not have a set of principles to make fair decisions about what health care resources should be publicly funded. Although the Canada Health Act requires the provinces to provide reasonable access to medically necessary services, it fails to define what constitutes reasonable access or what medically necessary means.

Let's think together for a moment about what principles should guide fair resource allocation decisions.

First, we would want a principle of efficiency which requires strong evidence of important clinical benefit worth the cost.

Second, we would want a principle of need which requires an impending risk of death or severe harm which could be reduced by the treatment, in the absence of other treatment options.

Third, we would want a principle of democratic process which requires public input on resource allocation decisions so public values could be included.

Combining these principles, it seems reasonable to fund a proposed service if it satisfies the principle of efficiency, OR the principle of need; AND the principle of democratic process.

This approach is an example of how we could state publicly the principles we will use for resource allocation decisions in our stewardship of public resources. It is a beginning, but I want to point out that we don't have any other set of principles that I am aware of to articulate what we will publicly provide in health care. Our only option now is to shout "medically necessary" – the meaningless term from the Canada Health Act -- at each other.

Death

Canadians awoke on May 7 to discover that a Halifax doctor, Dr. Nancy Morrison, had been charged with first degree murder in the death of a patient.

There is a publication ban, so the full details of this case are not known, but let me speculate that this case may turn out to be about euthanasia, or "mercy killing."

Consider the following scenario. A patient is dying, and will likely die that day. A decision has been made with the family to stop life support, and the life support machines have been disconnected. The patient appears to be suffering -- perhaps gasping for air. Drugs are administered to relieve the person's suffering. The patient is still suffering, and a doctor, acting out of compassion, administers a lethal dose that immediately stops the patient's heart and makes him dead.

As this case illustrates, there are three separate practices at the end of life -- withdrawing life-support, palliative care, and euthanasia.

Withdrawing life support means stopping machines like a breathing machine at the request of a patient or the family of an unconscious patient.

Palliative care means administering drugs, like morphine, to relieve symptoms, the most frequent of which is pain.

Euthanasia means administering a lethal injection and making someone immediately dead.

Withdrawing life support and palliative care are ethical, legal, and important aspects of good medical care. Euthanasia is ethically controversial and clearly illegal -- it can invoke a murder charge.

The issue for police and crown prosecutors in a case like this is to relate what the doctor did to the technicalities of the criminal code and criminal sentencing.

The problem is that the criminal law does not differentiate between the doctor, acting out of compassion, who administers a lethal dose to a dying patient and a person who walks into the corner grocery store and shoots the clerk in the head during a robbery. Both the doctor and the robber could be charged with first degree murder, and if convicted, both would be subject to the minimum penalty for first degree murder -- life imprisonment, with no parole eligibility for 25 years.

What has happened in previous cases of euthanasia by physicians? In a 1993 case, Dr. Alberto de la Rocha was initially charged with murder but ultimately convicted of the lesser criminal code offense
of injecting a noxious substance. He never went to jail.

The correct place to resolve the issue of euthanasia in Canada is in our democratic institutions – the Supreme court and the federal parliament.

But the real issue in these euthanasia cases is why euthanasia was thought to be necessary in the first place. These cases ought to focus attention on how we die, and want to die, in Canada.

What would you like your last day to be like? Probably you have conjured up in your mind a scene at home, surrounded by your loving grandchildren, at peace, comfortable, with a sense of completion to your life.

Unfortunately, you are probably more likely to die in a hospital, alone, in the middle of the night or perhaps in an intensive care unit hooked up to life support machines and in pain.

What can we do to avoid this? The solutions are local, and involve families and health care institutions.

In our families, we can talk about how we want to die, in advance. This is called advance care planning, a process that families can use to consider future health care decisions and about who ought to make them if a person can no longer make decisions herself. The University of Toronto Joint Centre for Bioethics has developed a tool to facilitate advance care planning called the University of Toronto Joint Centre for Bioethics Living Will. This is available free of charge on the world wide web at our website – http://www.utoronto.ca/jcb.

What can our health care institutions do? They can examine how people actually die. What was the family's perspective on how their loved one died? Was pain controlled? Was life support used appropriately? Did the person have a chance to die at home if desired? Did they receive spiritual counseling if desired? Were they at peace? Answering these questions, which are never systematically asked, will provide a clear indication of how to improve dying.

With the exception of the high profile euthanasia cases, how Canadians die is largely a secret issue which we don't like to confront. And yet, we can pursue simple local solutions within our families and health care institutions, to improve dying in Canada.

DNA

In March of this year we found out about Dolly, a cloned sheep from Scotland. Dolly was on the cover of Time and Newsweek.

Genetics provides an example of the amazing progress of science that also brings with it tremendous ethical and social implications. There are many social implications of genetics we could discuss, but let's take one example – genetic research on human subjects.

The ethics of research on human subjects is a tremendously important issue. It was born in the crimes committed in the name of science by the Nazis and the resultant Nuremberg code for ethical conduct of research. Unfortunately, research abuses have also occurred in the latter half of this century. For instance, two weeks ago President Clinton apologized on behalf of the US government for the notorious Tuskegee study, in which poor African American men were followed to study the natural history of syphilis, and not treated with antibiotics even after effective treatment for syphilis became available.

The three fundamental principles that guide research with human subjects were elaborated about twenty years ago. These so-called Belmont principles of respect for persons, beneficence, and justice lead to the requirement for informed consent, that the benefits of the research outweigh the risks, and that vulnerable populations are not exploited.

But genetics raises a whole new issue. Genetic disease occurs in families and in communities. This is not well addressed by the standard principles.

In many genetics research studies, blood samples must be collected from a whole family in which a disease exists to discover the responsible gene. For instance, think about what disease occurs commonly in your family. Now imagine that your sister is participating in a research study of the genetics of that disease. She calls you and asks you to participate too. Do you want to know whether you the carry the gene? What about your children – should they be tested? What principles and values should guide these decisions?

Also, genetic disease occurs in communities. For instance, about 1% of Ashkenazi Jewish women carry the gene for breast cancer – ten times the rate of non-Jewish women. Linking a gene – like the breast cancer gene – to a particular community – like the Jewish community – can produce major benefits and harms – in terms of stigmatization -- for that community.

These issues related to families and communities are not addressed by standard approaches to the ethics of research with human subjects. Although the last draft of the new code for research on human subjects being developed in Canada by the three major federal research granting councils took account of this issue, it treated all communities as identical. But there are major differences between different kinds of communities – first nations communities, the Jewish community, people with HIV/AIDS – differences in legitimate political authority, differences in methods of consultation, differences in the extent to which people in those communities actually identify with the community.

The University of Toronto Joint Centre for Bioethics, through its genetics and ethics research network led by Dr. Charles Weijer, is working on the issue of community in collaboration with the bioethics centre at the US National Institutes of Health. The likely result will be the addition of a fourth principle – respect for communities – to the Belmont principles of respect for persons, beneficence, and justice, that guide ethical research with human subjects.

Conclusion

Ethical issues at the frontiers of health care are not just newspaper headlines. They touch the lives of Canadians every day. Medicine and science are capable of amazing feats. But as a society, we must be able to distinguish between what we *can* do, and what we *should* do. As technological progress marches into the 21st century, we have to ensure our knowledge does not outpace our wisdom. Thank you.