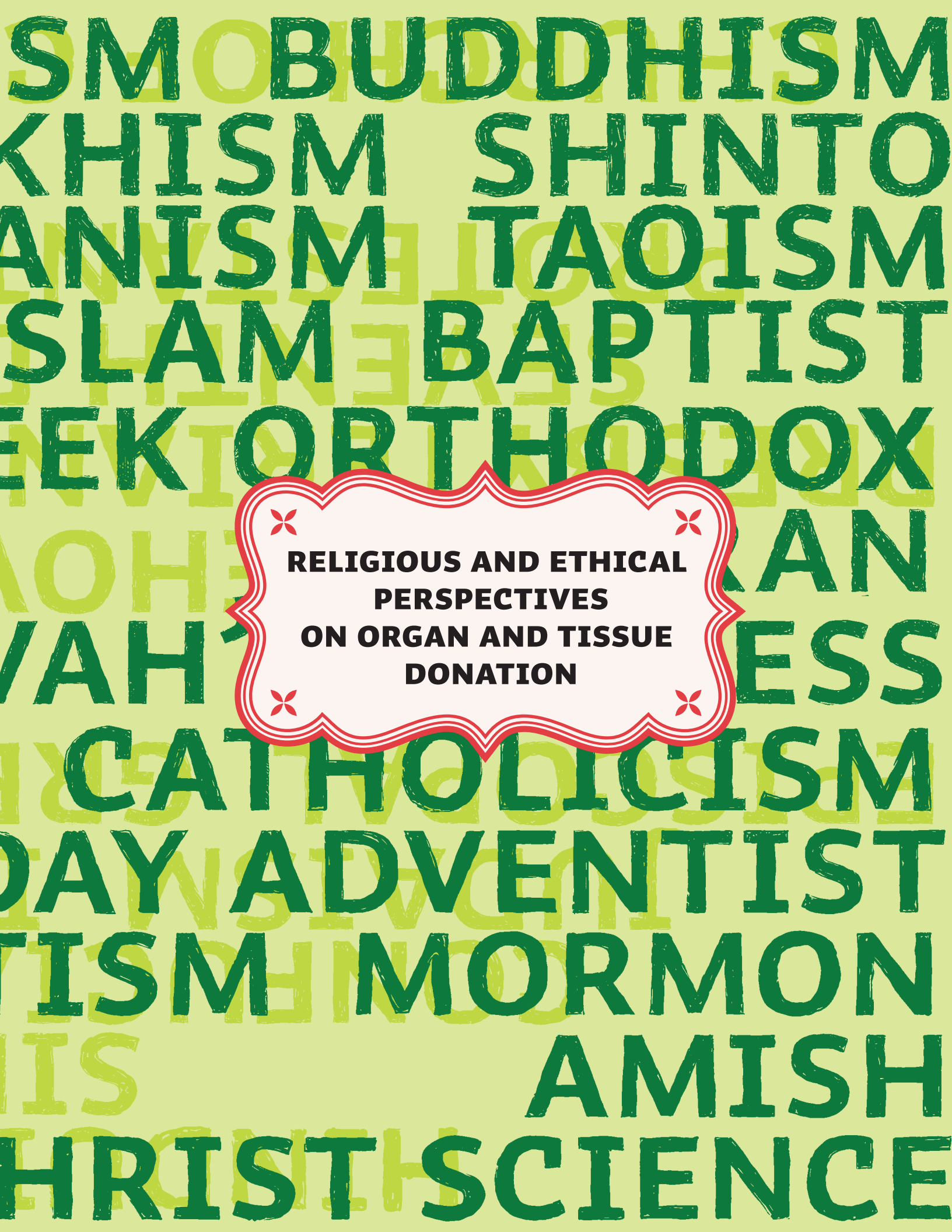
BUDDHISM
SHINTO
TAOISM
BAPTIST
ORTHODOX
CATHOLICISM
ADVENTIST
MORMON
AMISH
SCIENCE
RELIGIOUS AND ETHICAL PERSPECTIVES ON ORGAN AND TISSUE DONATION

One Life…Many Gifts is a curriculum resource to educate senior secondary school students about the vital importance of organ and tissue donation and transplantation. It brings to life the drama, generosity and the life-saving promise of donation and transplantation.

RELIGIOUS PERSPECTIVES

Culture and religion play a significant role in end-of-life experiences, including how people respond to illness, how grief is demonstrated, what rituals are important at the time of death and which members of the family are present.

Most major religions support organ and tissue donation as an honoured and compassionate expression of generosity and love. Beliefs about tissue donation vary as some groups may consider tissue donation life enhancing, and distinguish it from organ donation, which is more often life-saving.

AMISH

Amish consent to donation when it benefits the health and welfare of the transplant recipient. They are reluctant to donate if the transplant is unlikely to succeed or if organs will be used for research.

BAPTIST

Within this religion, organ and tissue donation is a matter of individual choice.

BUDDHISM

Buddhists have no official position on organ or tissue donation. It is a matter of personal choice and of the attitude of each school or tradition of Buddhism.

The Southern tradition permits autopsies and organ/tissue transplants; they believe that rebirth occurs immediately when a person dies. The Northern tradition believes that there is an intermediate state between "incarnations." They avoid movement or touching of the body for eight hours.

CATHOLICISM

Catholics encourage donation as an act of charity, and as a decision that belongs to each individual. There should be no undue pressure on someone to donate an organ. Ethical considerations must be taken into account. There can no commercialization of human organs.

CHRISTIAN SCIENCE

There is respect for an individual's choice.

CONFUCIANISM

They are traditionally against organ donation, but brain death was formally recognized in Korea in 2000 for the purposes of organ donation. There should be no damage to the body as a whole.

EPISCOPAL

There are no restrictions on giving organs or tissues for transplant.

GREEK ORTHODOX

The group supports donation of organs and tissues.

HINDUISM

There is no prohibition against organ and tissue donation.
It is a matter of individual choice.

ISLAM

Adherents to Islam strongly believe in the principle of saving human life. Followers permit organ transplantation as a priority in saving human lives – as long as the human body is respected and treated with dignity, and the sanctity and protection of human life are paramount; a person must give freely and without undue pressure, for the purposes of saving a person's life or to enable someone to perform an essential life function.

JEHOVAH'S WITNESS

Donation is a matter of individual choice. All blood must be removed from organs prior to transplant.

JUDAISM

All four branches of Judaism support and encourage organ and tissue donation. Within Judaism, there is a general principle that the "saving of a human life takes precedence over all other laws," including any delay in burial.

Organ and tissue donation is encouraged not only "for humanity's sake," but also "for God's sake, as a supreme expression of Godliness, of true, ultimate sharing: a religious act *par excellence*."

LUTHERAN

Donation is encouraged. There are no restrictions.

MORMON

Within Mormonism, the decision to donate an organ is a personal choice.

PRESBYTERIAN

Organ donation is allowed and encouraged.

PROTESTANTISM

Within Protestantism, there is respect for individual choice.

SEVENTH DAY ADVENTIST

The group strongly encourages donation and transplantation.

SHINTO

Followers are extremely cautious with regard to organ and tissue donation; families are concerned that they do not injure the "itai" – the relationship between the dead person and the bereaved family.

SIKHISM

Sikh philosophy and teaching place great emphasis on the importance of selfless service to others, and the performance of "noble deeds." The belief is "the physical body is a temporary abode of a person's soul, and it is the soul that is one's real essence." Organ and tissue donation is supported.

TAOISM

There are no objections to the use of parts of the body after death.

OVER TO YOU...

In almost all religions, there is support and encouragement for people who decide to donate organs and tissues. Not all people belong to an organized religion and some people do not accept the notion that there is a Supreme Being. There are many understandings of a Supreme Being, particularly in the area of there being someone who is a master designer of the universe. The entire humanist tradition, which does not depend on any particular doctrine or religion, acknowledges that humans have duties toward each other, but keeps the emphasis on this world, rather than on an afterlife. It is definitely worth your time to speak to people outside of your own faith tradition about their views on organ and tissue donation.

A. ORAL/WRITTEN PRESENTATION

Work in a group of six. Within this resource package, you have only a very brief description of each of the world's major religions and their position on organ donation. Each member of your group should choose a different religion or tradition, and gather additional information on the topic.

Specifically, you should read about the religion or tradition, and speak to a minister, priest, rabbi, imam and other faith leaders or philosophical thinkers to discover the ethical considerations that inform their thinking about organ donation and transplantation. There are holy books, including the Bible and the Koran, that speak to the question of what we owe each other as followers of particular beliefs.

When you have finished with your research and personal interviews, prepare a short oral and/or written presentation on the religion or philosophical position you have chosen. It can be very brief, three or four minutes in length. Share your findings with other members of your group and have a discussion about the common elements in the religions your group researched.

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B. EXPERT GROUP

Ask your teacher to call out each of the denominations and names of religions so that you can identify other students who have chosen the same religion or set of philosophical teachings you have selected. Make a second team that includes everyone who has researched the same topic. Compare notes. Is there any information that one person has found, in a book or through an interview or conversation, that can make the presentation you initially created even more substantial? If so, add this information to your original presentation.

C. CREATE AN INSPIRATIONAL POSTER

Finally, make posters that feature phrases, comments and quotations you have collected that you think would be of interest to have hanging in your classroom as daily reminders for living. The quotations should be ideas that are worth considering, or actions you think are noble or generous. It is useful to have observations and sayings that are helpful or provocative around us. Since you spend a lot of time in school, having one, two or even ten challenges, insights or other kinds of 'food for thought' can enrich your day.

ETHICAL CONSIDERATIONS – INTRODUCTION

ETHICS: The word *ethics* comes from the Greek word *ethos* (character) and the word *morality* comes from the Latin word *mores* (customs). Together, the two words combine to define how individuals choose to interact with each other. In the discipline of philosophy, ***ethics*** defines what is good for an individual and for society. It also establishes the nature of duties that people owe themselves and one another.

(Cornell University Law School. Last modified June 11, 2007, by Sarah Cochran.)

When is an organ not just pieces of tissue, muscle, veins and arteries?

Answer: When it is housed in a human being.

There are many ethical issues that are raised when discussing organ and tissue donation and transplantation. For example, should a dying person be able to buy an organ from a willing living donor? Should limits be placed on the amount of tax dollars that go toward keeping a sick patient alive? And should it be presumed that everyone is an organ donor unless he or she formally opts out of the donor pool? This section will allow you to explore your thoughts on many of these controversial issues.

ETHICAL CONSIDERATIONS –

THE BUYING AND SELLING OF ORGANS

The buying and selling of organs is illegal in Canada. Donation of organs and tissues in Ontario is legally governed by the *Trillium Gift of Life Network Act* 2000, c.39, ss.1 9(2). Similar legislation exists in other Canadian provinces. The *Trillium Gift of Life Network Act* sets out the conditions under which both living donations and deceased donations are legally allowed. In both cases, the statute requires explicit consent before organs can be removed and used for transplantation.

As well, the *Trillium Gift of Life Network Act* explicitly prohibits the buying and selling of organs and tissue. Section 10 states: "No person shall buy, sell or otherwise deal in, directly or indirectly, for a valuable consideration, any tissue for a transplant, or any body or part or parts thereof other than blood or a blood constituent, for therapeutic purposes, medical education or scientific research, and any such dealing is invalid as being contrary to public policy." So, for example, a person in need of a kidney transplant may not legally buy a kidney, and a person in financial need may not legally sell one of his or her kidneys. Nor may anyone help arrange for such a transaction.

This legislation makes the acquisition of transplantable organs and tissue a matter of voluntary, intentional gift-giving – of generosity to others. However, in some other countries, buying and selling organs is allowed.

As you have learned, Canada has a very low organ donation rate and in Ontario, one person dies every three days waiting for a life-saving organ transplant. Some Canadians who are waiting for a transplant and fear time will run out travel to other countries where buying and selling organs occurs. Some begin this process by arranging their purchase over the Internet.

There are many ethical issues associated with the buying and selling of organs, not the least of which is that people who make the desperate decision to sell an organ often face post-surgery complications with no medical care or lose the money they were promised to a broker who arranged the sale.

You can imagine the desperation of the waiting patient as well as the desperation of the person selling his or her body part due to poverty.

Given that the buying and selling of organs and tissue is illegal in our country, and given there are so many people waiting for transplants, one solution is to encourage more Canadians to consider donation and talk to their families about their wishes.

You can read through the entire Trillium Gift of Life Network Act *by clicking on the link at www.giftoflife.on.ca under "About TGLN."*

OVER TO YOU...

A.

DEBATE

On one side of the classroom, the people who support the idea of buying and selling organs should gather in small groups of three or four students. On the other side of the room, the students who oppose the idea of buying and selling organs should convene in small groups as well. Each group should create a brief position paper based on its initial opinions, about a page in length, in which the group defends its opinion. Choose one person to transcribe the ideas generated within the group. At the conclusion of this task, the group should have a well-organized, thoughtful, 500- or 600-word defence of whichever position the group thinks is worthy. There are only two choices – *Yes* or *No*.

As a next step, choose someone from your group to engage in a debate in which he or she presents the group's arguments. Ask the teacher to be the moderator and judge. You may want to invite students from another class to be judges as well.

B.

RESEARCH AND REFLECTION ON DEBATE

Read the article *Soliciting Kidneys on Websites: Is it Fair?* The journal article, co-written by Senior Bioethicist Linda Wright from the University Health Network in Toronto and Michael Campbell, Research Assistant, Bioethics Department, Mount Sinai Hospital, examines the relatively new practice of ordering organs on the Internet. Both the *yes* and the *no* sides of the debate are explored, together with an articulation of possible solutions to the problems posed by the increasing numbers of people who will do virtually anything to obtain an organ.

When you have finished reading the article, check back over your own notes from the debate exercise. Are there any arguments presented in the article that your group did not consider in your original debate? If so, add them to your group's position paper.

Ethical Issues in Dialysis
Aaron Spital, Series Editor

Soliciting Kidneys on Web Sites: Is it Fair?

Linda Wright*† and Michael Campbell†

*Joint Center for Bioethics, and †University Health Network University of Toronto, Toronto, Ontario, Canada

ABSTRACT

The Internet serves as a meeting place where people in need of kidney transplants can find strangers willing to donate. While Good Samaritan donors located via the Internet increase the number of kidneys available for transplantation, they also raise ethical issues. This practice alters the pattern for distributing kidneys from unrelated living donors and raises questions of justice in the allocation of organs. It is unclear if commercial forces are at play in the arrangements made between potential donors and recipients via the Internet. While it is unfair that some recipients do not have suitable, willing living donors, Web sites help to balance the inequity by increasing the opportunity to find a living donor; they also benefit other potential recipients by reducing the waiting list. However, although these Web sites are probably here to stay, Internet donor–recipient matches can have negative consequences that we need to minimize. Suggested strategies include regulated, monitored Web sites and the development of more anonymous organ donor programs.

The Issue

Recent media coverage has highlighted the work of MatchingDonors.com (1), a Web site where people advertise their need for a kidney for a fee ranging from US$19 for a 1 week trial to US$595 for an indefinite period. People who wish to donate can select a recipient based on information in the recipient's advertisement. While some may be concerned by the introduction of a commercial element to this enterprise, the service offered seems to be popular and has already resulted in a few people receiving kidneys, reportedly without money exchanges between the donors and their recipients. While American law prohibits the sale of organs, solicitation of living donors itself is not illegal (2). Kidney donor Web sites seem to be a natural extension of modern life. These days we turn to the Web when we are unable to find the goods we want on Main Street. What do such Web sites mean for potential recipients who do not enroll in a private Internet matching program for organ transplants, and is this form of matching donors and recipients ethically acceptable?

Relevant Facts

A number of important facts have been established: 1) transplantation is the best treatment for most people with end-stage kidney disease (3); 2) the longer a patient is on dialysis prior to transplantation, the poorer the outcome after transplantation (4,5); 3) for a healthy person, the risk of donating a kidney is very low (6); and 4) kidneys from living donors provide excellent outcomes for recipients (7). With the wait for deceased donor kidneys currently being much longer than most people find acceptable, it is understandable that at least some potential recipients and their families will use whatever means are within their reach to find kidney donors (living or deceased).

Inequity of Transplantation from Living Donors

Some potential recipients are fortunate enough to have a willing living donor, while others are not. This constitutes a form of inequity resulting from chance. Some people may be willing to donate a kidney to someone they know, but not to a stranger.

By facilitating living donor transplants directed to strangers, we are helping not only the recipients of these transplants, but also patients on the waiting list for deceased donor organs by reducing the number of potential recipients competing for a limited supply of kidneys. In this way, matching Web sites help to offset inequity introduced by chance. Moreover, this practice does not harm people higher in the queue than the recipient of the living donor kidney, as these people still wait the same amount of time.

On-line recipients are fortunate to find donors, as are those with a friend or relative willing and able to give up an organ. Furthermore, participation in on-line matching programs does not prevent or interfere with other potential recipients from finding a donor on-line. While it may

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be unsettling to see someone receive an organ before a patient who is very ill and near the top of the waiting list, there has always been innate inequity as a result of biologic factors influencing allocation beyond the control of a rational ordering system. This is compounded by the fact that people are more likely to donate to someone they know rather than a stranger (8).

Objections to Web Site Solicitation for Organs

Justice

Online recruitment violates our notions of justice, as access is not equally available to all. Some potential recipients may not have the knowledge or linguistic proficiency to use this technology, and for some the monthly fee is prohibitive. (As of July 12, 2005, the fee for a 30-day advertisement on MatchingDonors.com was US$295) (9). There are those who are uncomfortable or less resourceful in requesting an organ. A more or less attractive profile may influence who is offered an organ through the media.

Allocation

Hospitals allocate kidneys from living anonymous donors to the next suitable recipient on the waiting list. However, organs donated via Web sites are directed to a particular recipient based on their profile on-line. Like living related donors, Web site donors choose their recipient, who then bypasses the waiting list. Where no anonymous donor program exists, a Good Samaritan's only avenue to donate is to use a donor Web site. Thus some kidneys that might have been offered to the waiting list are allocated to specific people, thereby disadvantaging others on the waiting list.

Financial Transaction

Although the number of centers accepting donors who have only limited or no acquaintance with the recipient is increasing (10), there are those who have reservations about this practice due to fears that organs may be exchanged for money. Transplant centers have a responsibility to ensure that they are not party to such commercialization, yet it may be very difficult for them to determine if the donor is being paid for the organ. Advertising for organs may appear to alter the landscape by subtly associating organ donation with a medium that is generally commerce based.

Informed Consent

Transplantation from living donors rests on the principle of voluntarism after full disclosure of risks and benefits of the proposed procedure. Concerns remain that potential donors may have misinformation or unrealistic expectations about the transplantation process based on information from the Web site. It is essential for transplant centers to address this by providing accurate information in an understandable format for all living donors. The assessment of donor suitability aims to identify a lack of knowledge, misunderstanding of information, or an absence of voluntarism.

Possible Solutions

Regulation

Some recipients-in-waiting seek a living donor from among family and friends via phone calls, e-mails, and face-to-face discussions. A network is built through these communications in the hope that someone will be a ready, willing, and compatible donor. Soliciting in this manner is not thought to be morally objectionable; it may be seen as an acceptable behavior for those who take responsibility to improve their health and lives. On the other hand, as just discussed, objections to solicitation via the Internet have been raised. These are not aimed at the technology per se, but at the potential to solicit strangers and mislead them. Yet strangers are likely to feel less obligation than family members or friends, suggesting that solicitation of strangers may be acceptable if it is accompanied by accurate information.

Regulations have been developed to control what is transmitted by technologies other than the Internet (e.g., telephone, news media). Regulation of living donor Web sites would be appropriate to ensure the safety of potential volunteers. Such a Web site could be monitored by staff who would review and post offers from volunteers willing to give a kidney. It could also be a place for potential recipients to post information about their needs and view messages posted by potential donors. Recipients-in-waiting could list personal information, but would be prohibited from offering goods or money as incentives for donation. The Web site may improve the informed consent process for potential donors as the information on risks, benefits, and issues such as time required for the procedure and recovery, financial implications, time away from work, etc., would be complete and accurate. The Web site should be made freely available to dialysis units, the staffs of which could help willing patients to register, thereby achieving greater equity of willing access.

Anonymous Donor Programs

By developing more anonymous donor programs, we will increase the number of living donor kidneys available to those on established waiting lists who lack living donors. Such programs will also provide more opportunities for those who wish to give a kidney to a stranger to do so without having to resort to Internet matching sites. There is a growing experience with nondirected organ donation that has demonstrated that this can be done ethically. Established nondirected living kidney donor programs have shown that it is usually possible to identify those donors who are suitable for this procedure and those who are not. Many of these Good Samaritan donors have reported that they do not regret their actions and are happy they donated (11). Yet the number of transplant programs in the United States and Canada that accept nondirected donors is small. Transplant centers

should, at the very least, encourage debate on this issue and provide a forum where potential and past donors and recipients, clinicians, and the public can discuss their concerns and offer suggestions.

Conclusion

Donor Web sites may help fill a gap between kidney supply and demand by assisting people who are willing to donate a kidney but wish to have a say in who will receive the gift. These Web sites will probably continue to operate because there are volunteers who want to choose their recipients and because there are so many people with end-stage renal disease who are desperate for a transplant. While some of these sites may be viewed as unjust, it may be possible to establish ones that are acceptable. Health care professionals have an obligation to advocate for their patients. Therefore they must strive to increase organ donation in an effort to provide organs for all potential recipients. Turning away willing living organ donors may deny potential recipients the possibility of improved health and longer life. Here we have the opportunity to increase organ donation by living donors in two ethically acceptable ways: increasing the availability of anonymous donor programs and establishing regulated Web sites that enable more people to find a willing living donor. Instead of shunning Web site donors who approach transplant centers in the spirit of generosity, we should seriously consider those who are willing to give such a precious gift to someone in need.

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C. PERSONAL REFLECTION AND DISCUSSION

Before you make a final judgement on the practice of the buying and selling of organs, ask yourself this question: "If I needed a kidney or a liver, would I be prepared to pay for it to save my life, even if I knew that it was illegally purchased or taken from someone who was too desperate to turn down the fee?" Don't answer this question glibly or lightly; remember that you are basically choosing whether to live or die. Share the reasons for your answer with the class.

ETHICAL CONSIDERATIONS –

PUBLIC RESOURCES and PERSONAL RESPONSIBILITY

Canada has a publicly funded universal health-care system. For those of us who have lived our entire lives in a Canadian province or territory, it is astonishing to read about people who have been forced into bankruptcy or who have had to sell their family homes to pay for life-saving operations.

Certainly, none of us would die because we did not have private medical insurance or lots of money in the bank. In the United States, the health care we often take for granted is currently an impossible dream for 47 million people.

Although we do not pay directly for x-rays, blood tests, medical appointments, surgical procedures or hospital stays, obviously it costs money to provide health care – and it costs a lot of money to address the multiplicity of medical problems presented by a potential organ recipient. Medical and psychological assessments have to be conducted on each potential patient. The Trillium Gift of Life Network has to be staffed by experienced health-care professionals 24 hours a day, 365 days a year. Telephone calls come in from all over Ontario, letting the network know about potential organ donors. Matches have to be made with potential recipients; hospitals have to be alerted and patients have to be contacted. Concurrently, surgeons, who are always involved in a daily roster of hospital surgeries, stand by for transplant emergencies.

Each transplant operation requires a battery of tests, a hospital bed, nurses, an entire surgical team and a post-operative hospital stay. Additionally, over time, one needs to include the costs of the immunosuppressive drugs required to avoid organ rejection. They are taken daily, for a lifetime.

In 2005-2006, estimates were prepared by the Ministry of Health and Long-Term Care for the costs of adult transplant procedures in Ontario.

Kidney:	*$ 24,792*
Liver:	*$ 82,400*
Lung, heart/lung:	*$ 111,120*
Pancreas, kidney/pancreas:	*$ 74,400*
Heart:	*$ 52,802*

Of course, not every person who has liver, lung, heart or kidney disease receives an organ, and sometimes a transplanted organ fails. In the interim stages, when a patient is waiting for an organ, or for treatment prior to a second transplant attempt, ongoing medical care has to be provided in order to maintain a person's life. The annual Ministry of Health funding for the treatment of kidney disease patients undergoing hemodialysis in a health-care facility is approximately $55,224, based on the 2006 rate – about twice as much as a kidney transplant. The costs of ventricular assist devices, which are used to assist patients whose hearts are failing, are between $90,000 and $126,000 each year for each person.

OVER TO YOU...

A. POLL OPINION AND ANALYZE

You are a current or future taxpayer. Do you feel that there should be any limits on how much money is spent on organ transplantation?

As you consider the question, you need to examine the degree to which you want to hold individuals accountable for their own health. For example, if a person is smoking, drinking, sitting on a sofa, eating junk food and doing nothing to remain physically fit, should he or she still be able to draw upon the medical resources available in our country? Write your response, and share it with a person sitting in front of you, behind you or beside you.

Tally up the answers in the entire class. How many students want some kind of lifestyle judgment passed on a potential organ recipient? How many people feel that all sick patients who are eligible to be placed on an organ waiting list should be accepted, irrespective of what they may or may not have done before their illness and need for an organ?

(Keep in mind that there is an extensive interviewing and examination process undertaken before a potential candidate is accepted as a possible organ recipient. People do not just show up at a doctor's office and place themselves on a waiting list. The general health of a patient is assessed; his or her willingness to comply with doctor's instructions after surgery is explored; and the capacity to survive a major operation is evaluated.) Now, make your decision about the eligibility of potential organ recipients.

It is unlikely that the class will split 50-50. When you examine the results, discuss the reasons why you think you have so many – or so few – students who want to give an organ to anyone who is eligible, based on the criteria established by the nine hospitals in Ontario that do transplants.

B. CREATE A TIP SHEET

There is no net gain in trying to convince people to watch less television, or cut back on video games. They won't do it or, if they do, it would only last a week or two. Over time, the remote control would find its way back into the family room or living room. Fear campaigns, long used to cut down or eliminate drinking or drug use, have rarely worked. People do not respond to fear tactics.

If you are not going to try to scare someone into a balanced lifestyle, what strategies can you create to encourage people to eat healthier foods and get outside to bike, walk, play street hockey or rustle up some friends for a basketball game?

Limit yourself to **three** ideas that will enhance people's motivation and are actually likely to succeed. For example, suggesting that all fried foods, soft drinks and sugar products be removed from a person's daily diet is not likely to appeal to most people as a reasonable plan of action. Discuss your ideas with a partner and create a tip sheet for elementary school students to encourage active, healthy choices.

C. GATHER AND SUMMARIZE PERSPECTIVES

The Scientist, a magazine of the life sciences, reports a recent breakthrough in the treatment of bladders. During the past 100 years, patients have undergone a procedure called cystoplasty to repair a dysfunctional bladder. Now, using cells from a person's own bladder, a new one can be created in laboratory conditions within six to eight weeks. The author of the article asks, "Will you soon be able to buy your own bladder?" The answer seems to be *yes*.

Choose a partner and decide whether you think there should be limits on what science should try to do, with humans and with animals. With your partner, consider these questions and write a summary of your viewpoints:

Are you in favour of allowing the scientific community to explore, build and create anything it can imagine?

Do you think that legislators should pass laws to limit some areas of scientific investigation?

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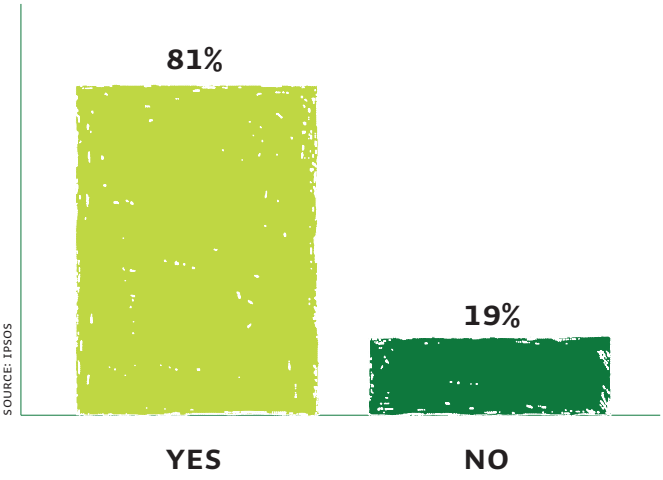
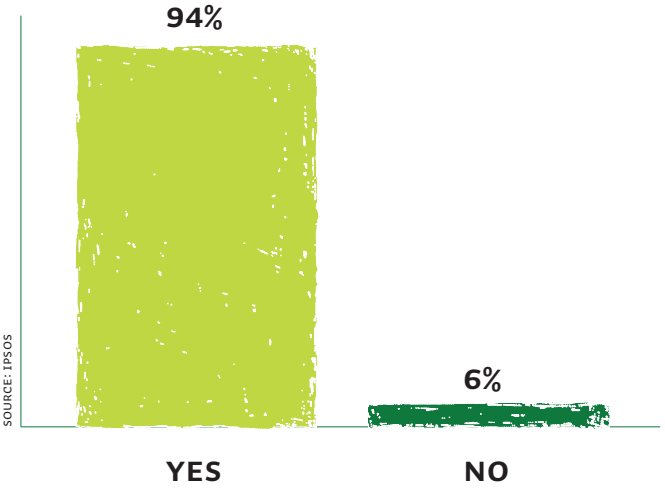
ETHICAL CONSIDERATIONS –
PRESUMED CONSENT VS. INFORMED CONSENT

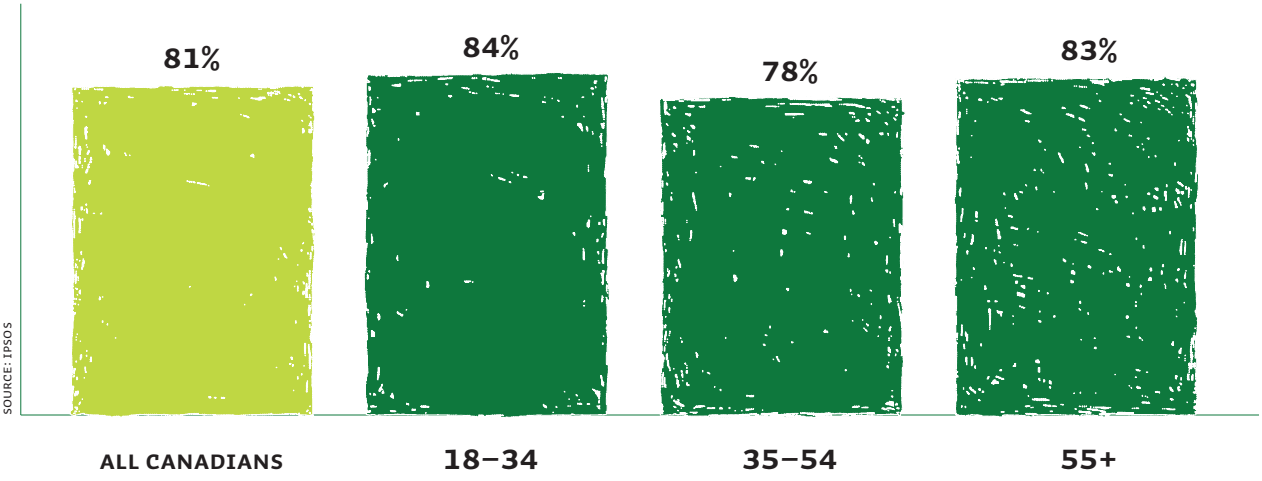
WILLING TO DONATE ORGANS FOR TRANSPLANTATION AFTER DEATH



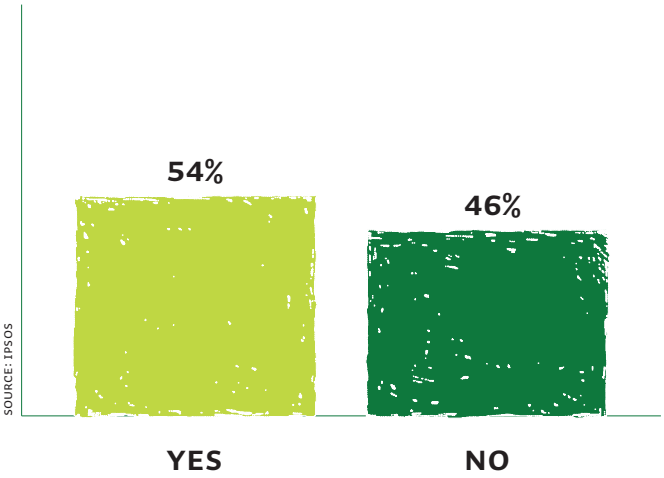
IN FAVOUR OF ORGAN DONATION FOR TRANSPLANT



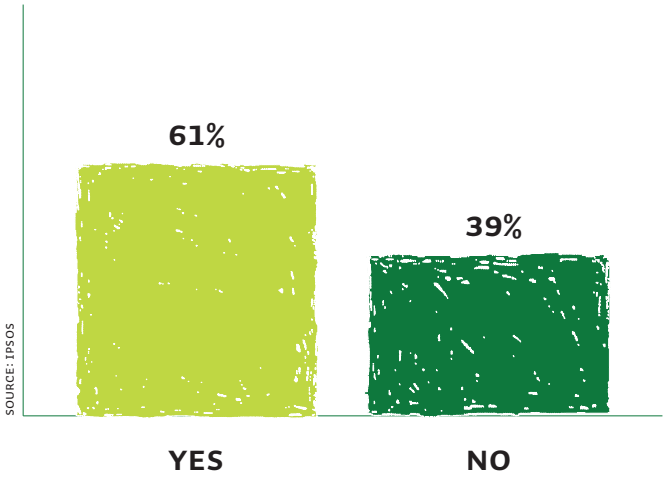
WILLING TO DONATE ORGANS FOR TRANSPLANTATION AFTER DEATH BY AGE



CARRY DOCUMENTATION THAT INDICATES WILLING TO DONATE ORGANS



TALKED TO FAMILY ABOUT WISHES ON ORGAN DONATION



In Canada, an Ipsos Reid survey undertaken in June 2006 discovered that 81% of Canadians are willing to donate their organs for transplantation after their death. The percentage is even higher among young people between the ages of 18 and 34. Eighty-four percent of men and women in that age bracket are willing to donate their organs for transplantation. Among the entire Canadian population, virtually everyone is in favour of organ donation – 94% of all Canadians support the idea. However, despite the almost universal approval, only about half of all Canadians have signed a donor card or carry documentation that indicates they are willing to donate organs. And only 61% have informed their loved ones about their donation wishes.

The same problem exists in Britain. Ninety percent of the population support organ donation, but only 23% of the people who live in England have actually registered their wish to donate. Faced with the reality that hundreds of people die each year because there are not enough donors, some countries have adopted a policy known as *presumed consent*.

What *presumed consent* means is that the government assumes that you **do** want to donate organs after your death unless you have specifically indicated that you **do not** wish to donate – people are asked to *opt out* of the system. Among those countries that have a policy of *presumed consent*, donation rates are 25–30% higher than in countries that have *informed consent* practices. In Canada, people are asked to sign a donor card or indicate their wishes on a registry; final consent for donation rests with the family – people are asked to *opt in* to the system. That option is considered *informed consent*.

Two senior bioethicists, Linda Wright of the University Health Network and the Joint Centre for Bioethics, University of Toronto, and Veronica English, the Deputy Head of Medical Ethics, British Medical Association, have written an article in which Veronica English argues that *presumed consent* is the only solution to the shortage of organs and Linda Wright argues that *presumed consent* will not answer the problem. Read the article:

Is presumed consent the answer to organ shortages?

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YES In the UK in the year to 31 March 2007, 440 people died waiting for a donated organ (UK Transplant, personal communication). At the same time bodies were buried or cremated intact—it seems likely that this was not because those people objected to donating their organs but simply because they never got around to making their wishes known. Surveys show that 90% of the UK population support organ donation,[1] yet our current law assumes, when people die, that they are in the minority who do not wish to donate. By changing the default position to presumed consent—assuming people want to donate unless there is evidence to the contrary—we can help save and transform more lives while respecting the wishes of those who want to donate and protecting the rights of those who do not.

Although 90% of the population support donation, only 23% have registered their wish to donate,[2] and so the decision falls to the family when they have just been told that their relative has died or is dying. Not surprisingly, when they do not know their relative's wishes a large number (40%) opt for the default position, which is not to donate.[3] Despite major efforts to improve transplantation rates over the past decade—through publicity and education, simplifying the registration process, and changes in legislation—the gap between the number of organs available and the number of people needing a transplant shows no sign of narrowing and the waiting list for organs stands at an all time high.[4]

How would presumed consent work?

Presumed consent is often portrayed in its extreme form where, if an individual has not opted out, the organs will automatically be available for donation. However, the system proposed for the UK would continue to involve the family.[5] Before a change to presumed consent there would be extensive publicity advising people how to opt out. Mechanisms must be in place to ensure all sections of the public are informed and can register an objection easily.

With the new system in place, when a person is identified as a potential donor doctors must check the opt-out register. If the person has not opted out, the relatives are informed and, as an added safeguard, are asked if they are aware if the person has any unregistered objection. If the answer is no, the relatives are informed of the intention to proceed with donation. However, the organs would not be used if it would cause severe distress to the relatives. In this way, relatives are still involved but the approach is easier for all concerned.

Of course, the key question is does it work? It is notoriously difficult to prove a causal relation between particular determinants and donation rates and to extrapolate from the experiences of one country to another. Nevertheless, careful analyses seem to indicate that presumed consent improves donation rates. Analysis of 28 countries found that those countries that consistently implemented a policy of presumed consent had higher donation rates than those that did not.[6] Abadie and Gay did a detailed regression analysis comparing 22 countries over 10 years taking account of determinants that might affect donation rates: gross domestic product per capita, health expenditure, religious beliefs, legislative system, and number of deaths from traffic crashes and cerebrovascular diseases.[7] They concluded that "When other determinants of donation rates are accounted for, presumed consent countries have roughly 25-30% higher donation rates than informed consent countries." One explanation is that, even if the family has the final say, countries with presumed consent legislation have fewer refusals.

The organs would not be used if it would cause severe distress to the relatives

Spain has the highest recorded donor rate in the world, at 35.1 donors per million population (compared with 12.8 in the UK).[8] So what can we learn from there? Spain has a presumed consent system (although in practice relatives are consulted) and has invested heavily in transplantation[9]: over a decade the number of transplant coordinator teams increased from 25 to 139.[10] This combination of a system of presumed consent, which portrays a positive attitude towards donation, major financial investment, and good organisation, seems to be the way forward.

Public attitudes

Any such change must have public and professional support. This seems to be increasing in the UK,[11] although we have yet to see the sustained education and debate that is required. It is not acceptable for the government to continue arguing that there is a lack of support for presumed consent without any serious attempt to test this assertion.

We all have the same aim: to improve donation rates. Current efforts to achieve this should be supported, but how long should we continue to doggedly pursue the same strategy that has failed, so dramatically, to improve donation rates over the past decade? We cannot afford to wait another five years before beginning to consider alternatives because the longer we procrastinate the more lives are lost unnecessarily. Now is the time for a public debate about presumed consent so we are ready to implement it when, as seems likely, we are having the same debate in five years' time.

A move to presumed consent is the way forward. It would be

- Good for those who support donation—because they have to make no effort to ensure their wishes are followed
- Good for those who oppose donation—because their wishes will be formally recorded and must be followed
- Good for families—because they are relieved of the burden of decision making when they have just been told their relative has died or is dying
- Good for those who need a transplant—because with more organs available more lives can be saved.

Competing interests: None declared.
References are in the full version on bmj.com

The supply of donor organs cannot keep up with demand. **Veronica English** argues that assuming people want to donate unless there is contrary evidence will increase availability, but **Linda Wright** believes the problem is more complex

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NO Presumed consent will not answer the organ shortage. It has not eliminated waiting lists despite evidence that it increased organ donation in some countries.[1] Systems of opting out do not ensure higher rates of donation than opting-in systems.[2] Strategies to encourage people to donate and public education seem to help and are independent of whether people have to opt in or out. The shortage of organs has multiple causes; no single strategy is likely to solve it.

Controversy over presumed consent

Presumed consent refers to laws that permit the procurement of organs without explicit permission.[3] The term is used widely in discussion of systems of opting in or opting out of organ donation. The US Institute of Medicine is concerned that the introduction of presumed consent without the appropriate public support could reduce donation rates in countries where autonomy is highly prized, such as North America.[4] People may be more likely to donate when they feel they retain control of that decision rather than the law dictating that donation should take place. Brazil had to withdraw its system of presumed consent because it aggravated mistrust in the healthcare system.[4]

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Influences on donation rates

The effect of presumed consent is hard to evaluate as it is implemented in different ways in different contexts, with different results. More organs may be available for transplantation because of the number of intensive care beds, transplant surgeons, coordinators, and specialised units or because of which organs are needed and the predominant cause of deaths.[5] The rate of donation in France in 2005 was 22.2 donors per million population while in Spain it was 35.1 per million.[6] Both countries operate presumed consent and routinely ask families for their consent to donation, yet their organ donation rates vary greatly. In Austria, where such permission is not routinely sought, the rate of donation was 24.8 in 2005.[6]

More people might donate if they were offered financial incentives

Spain expands its donor pool by using declarations of death based on not only neurological but also cardiocirculatory criteria—that is, declaring death when the cardiorespiratory system is believed to have stopped functioning. This system has been credited with increasing donation rates in some parts of the US, which has an opting-in system.[7 8] Singapore's law on presumed consent makes exemptions for Muslims on religious grounds.[9] The need for public acceptance of organ donation means that a strategy may work in one society, but not another.

Other factors that might explain Spain's enviable rates of organ donation include an environment that treats organ donation as a priority. Transplantation has a strong support system, a dedicated budget, and accountability for performance.[10] Staff are trained how to approach grieving families about organ donation. Donation will not increase without the necessary equipment, trained staff, and intensive care beds to enable a potential donor to donate viable organs. These institutional factors contribute to the donation rate and seem to account for some of the variation in rates of organ availability.[11]

Strategies to encourage donation

Currently organ donation is conceptualised as an altruistic act, and legislation exists in most countries to outlaw any material benefit for donation. However, more people might donate if they were offered financial incentives. Another possible incentive would be to give increased priority for a donor organ to people who have recorded their willingness to donate.[12] Tactics to identify those who want to donate and encouraging them to inform their families about their wishes would inform the procurement system about a donor's wishes and facilitate decision making on organ donation. Donor cards would surely help families decide whether to donate a relative's organs.[13]

We must not forget that many countries today are multicultural societies, where diverse groups view organ donation differently. Trust in the healthcare system is not universal. Presumed consent could alienate even further those groups that lack this trust, and feed negative attitudes towards organ donation. Engagement of the leaders of communities and attention to religious and cultural beliefs and practices around organ donation may help the public to build the necessary trust to favour organ donation.

Meeting demand

Given the challenge of comparing behaviours in societies with different belief systems and laws, it is imperative that we increase our knowledge of the variables influencing donation rates. Organ donation has increased in Spain, where presumed consent and additional strategies are used. Are some of these variables more effective than others? Are any or all of them adaptable and acceptable to other countries?

Finally, meeting the demand for organs may require not only increasing organ supply but also optimising prevention of disease and selection of recipients. Given the multifactorial nature of the problem, presumed consent alone will not solve the organ shortage.

Competing interests: None declared.
References are in the full version on bmj.com

OVER TO YOU...

CLASS DEBATE AND PERSONAL WRITING

We all should be interested in the rising problem of securing enough organs for waiting patients. You have now read articles that present both 'yes' and 'no' opinions on whether presumed consent is the answer to organ shortages.

i) When you have finished reading, write your support argument for the position you think would result in more organ donors. Make sure you include the reasons for your decisions.
ii) Find a partner who shares your position.
iii) Together, prepare a presentation in support of your argument. Give your presentation to a larger group in your class which has considered this question.

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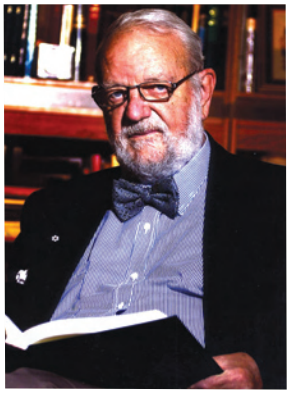
Photo by K. Stuart. London Health Sciences Centre.

TWO ETHICISTS' PERSPECTIVES:

JOHN B. DOSSETOR'S AND LINDA WRIGHT'S REFLECTIONS

As you have read through this section, you will have noted that there are many ethical issues that arise around organ and tissue donation and transplantation. There are ethicists in every teaching hospital in Ontario. The following two reflections represent the views of two of these ethicists.



Ethical Considerations in Kidney Transplantation

by John B. Dossetor, Professor Emeritus Medicine/Bioethics, University of Alberta

"Ethics" comes from a Greek word – 'ethos' – which means the 'customs, or ways, of a society'. "Morality" comes from the Latin word – 'mores' – which means very much the same thing, in that ancient language. They are both used in relation to what brings about, or promotes, good relationships and behaviours in a society or community. Thus, ethics helps us decide what we 'ought to do' to create benefit for ourselves and for the good of our society. Note that there is a difference between 'ought' and 'must.' Ethics involves 'choices' – choosing what we ***ought*** to do for our society – not laws or principles which we ***must*** obey – though laws are also necessary to meet other aspects of our lives, especially avoiding bringing harm to others.

So much for a few 'philosophical considerations.'

The Kidney Foundation of Canada, a partner in the development of this curriculum, is an ethically-committed organization which wants, very much, to help:

a) prevent us from getting those conditions that might lead to our kidneys failing us, and

b) those whose kidneys have failed to get access to high quality healthcare, including dialysis (purification of the blood by a machine) and the opportunity for each of them to have the transplant of another kidney so that they can be free of the machine. Such kidneys are in very short supply.

The problem, of course, is that – to date, anyway – the kidney that is transplanted must come from another person who has either tragically died (a 'deceased donor') or who is in good health but willing to live the rest of their life on only one kidney (a 'live donor'). Obviously, both types of donors are true heroes. And those who give one of their kidneys while still alive give a particular kind of gift and deserve our deep respect and admiration.

But why do you – yes, ***you*** – need to know about all this?

Well, there are a number of reasons:

- we need to be aware that affected people – patients in kidney failure – will die too soon on the machines that sustain them if we cannot find a human kidney to give them back the 'rest of their expected life';
- for some people, there is a certain 'yuk' factor in their perception of taking organs out of dead persons in order to meet this need and knowing more about the need and the process of organ donation and transplantation will help reduce this reaction;
- kidneys from living persons raise the possibility that they are not given freely, i.e., that the donation is forced on them in some way, such as by excessive pressure from others, or, in the case of live donors from 'the developing world,' for money to relieve the poverty of their family (a process which is nearly always carried out by dishonest 'commercial brokers' and often fails to relieve the needs of those people donating their kidneys).

Giving parts of one's body to another person, whether one is alive at the time of donation or has recently died, should be based on the ethical principle of ***'altruism.'*** This means, in effect, 'doing good for someone else without direct benefit to oneself.'

Everyone working to increase organ donation in our society asks individuals to be prepared to give a kidney to another person, ***for ethically altruistic reasons only***, after their unfortunate, and usually quite unexpected, death. I am writing this in the hope that you, the reader, will think about these matters, discuss them with your friends and with your family – and then make a resolution, sometime soon, ***to sign your donor card and register as a willing organ donor***, just in case…just in case tragic unexpected circumstances arise that could lead to your death. And to record this decision in such a way that your caregivers at that tragic time will know your decision and carry out your altruistic wishes toward an unknown recipient who, you can be sure, will ever after be grateful to you.

Linda Wright, Senior Bioethicist, an interview from her office in the Toronto General Hospital:

"No matter how much we need organs for transplantation, we cannot buy them and we should not go into the marketplace, looking for spare parts."

While scientists are searching for new ways to prolong the life of donated organs and surgeons are struggling to extend the lives of recipients, there are a number of people who work within the medical environment – one step removed from the day-to-day decisions a transplant surgeon has to make. Linda Wright is a senior bioethicist at the University Health Network. Wright deals with the dilemmas of donation – who should give, who should receive, who can buy or sell organs. How those decisions are made, and how they are translated into public policy, make a very real difference to the kinds of medical services we can and cannot support ethically.

One of the ways we distinguish ourselves as Canadian citizens is that we have a universal health-care system. Although many of us take that gift for granted, we only need to look at the United States to appreciate the significance of our OHIP cards. Health care is more precious than almost anything else we receive from our government. Not only does our health-care system provide for the relatively minor medical problems we have – the flu, stomach upsets and broken limbs – but the health coverage also extends to very serious maladies – including all kinds of cancers, heart and lung diseases, even organ transplants. In the U.S., medical bills account for 50% of all personal bankruptcies. In Canada, no one (with the exception of First Nations and Inuit people) goes without first-rate medical and surgical care. We have an excellent medical safety net. Virtually all procedures have standard protocols and a variety of safety checks. That covers the physical territory. There are other landscapes that also require attention; chief among them are the ethical dilemmas.

There are a number of ethical concerns that have already been discussed by politicians, and passed into law. In Canada, we cannot sell our blood. We cannot sell our organs or tissues. There is ongoing debate in some countries about whether we should assume that everyone wants to donate their organs when they die, unless they specifically say that they do not want to participate. A desire to donate is presumed. Canada uses an 'opt-in' system where potential donors need to indicate a willingness to become a donor. We want explicit proof that someone has agreed to donate his or her organs. Wright, in the article included within this booklet, is very clear about presumed consent. First, she thinks it is an oxymoron. She feels that there is no such thing as presumed consent. Also, Wright does not think changing the notion of consent will answer the donor shortage in our country.

That leaves the organ shortage issue unresolved: how can we increase the number of donors? Is it ethical to let people die because there are no organs available? Wouldn't it be better if citizens could sell their organs, allowing other people to live? Wright is adamant in her opposition to the idea: she worries first about the commodification of the body, treating our bodies as a store in which various *things* (kidneys, hearts, lungs) can be bought and sold. She also struggles with the question of whether someone is selling an organ voluntarily. Is the so-called *free* choice driven by poverty, by a desire to feed a family when there are no other financial options? Rightly, Wright worries about pressures placed on people, pressures that are coercive by their very nature: "Nothing to do with humans is ever airtight."

Even without money changing hands, Wright worries about decisions around organ donation within families. If a sibling has an organ that would be a match for a brother or sister, does he or she have an obligation to donate the matching organ to another family member? For Wright, the answer is straightforward. She feels that a parent has a duty to a child, but brothers and sisters have no obligations toward their siblings. On this question, Wright is very certain about her position: "We should not plunder the organs of children, even if it means an enormous benefit to another child within the family. No one under the age of 18 is in an emotional position to offer informed consent. Can you imagine the pressure parents could place on a child, the guilt a child would be asked to carry if he or she said *no*. That's why the question should never arise."

For Wright, the question of soliciting organs is always just under the surface. Since there are not enough donors in Canada for people on the waiting lists, you have a situation where a very wealthy person may well be tempted to approach highly vulnerable people for an organ. It wouldn't even have to be the case that a rich family member would want to opt out of the public system. Anyone who is desperate will want to save his or her life or that of a loved one. That is why Wright thinks it is so important that we, as a society, agree on the principles by which we will govern ourselves.

As new technologies emerge, new questions will arise, and ethicists – like Linda Wright and Dr. John B. Dossetor – will wrestle with colleagues, in Canada and across the world. As a citizen yourself, you should be considering these ethical questions. Organ donation and transplantation are hot topics, and they are likely to remain on the political agenda during your lifetime. At some point, you may be asked to vote on the efficacy of various policies related to the buying and selling of organs, and the wisdom of using stem cells to repair existing organs and create new ones from donor tissue. You should know where you stand.

OVER TO YOU...

DEFEND A POSITION

Working with a partner, identify and list in point form the major ethical arguments John B. Dossetor and Linda Wright make in their final reflections. On your own, choose one argument and write a paragraph where you agree or disagree with one of their perspectives. Share your paragraph with your partner and discuss your viewpoints.

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One Life…Many Gifts is a curriculum resource to educate senior secondary school students about the vital importance of organ and tissue donation and transplantation. It brings to life the drama, generosity and the life-saving promise of donation and transplantation.

Funding for this project has been provided by the provincial Ministry of Education and the Ministry of Health and Long-Term Care. This project would not have been possible without their support or the generosity of an anonymous Ontario resident whose contribution ensures that students in the province understand the life-saving promise of organ and tissue donation and transplantation. The Steering Committee sincerely thanks all of our supporters.

The development of this curriculum has been co-sponsored and coordinated by the Trillium Gift of Life Network, the Multi-Organ Transplant Program at London Health Sciences Centre and The Kidney Foundation of Canada.

Educating secondary school students and their families about the need for organ and tissue donation and the success of transplantation was originally initiated in the London region in 2000. With funding received from The Kidney Foundation of Canada, the Multi-Organ Transplant Program at London Health Sciences Centre had the vision to develop a unit of study, *One Life…Many Gifts*, working with both the Thames Valley District School Board and the London Catholic District School Board. The original program was used in Healthy Active Living Education, Grade 11, Open (PPL30) in Ontario's curriculum. The curriculum resource before you builds on the vision and foundation provided by this original program and the Steering Committee gratefully acknowledges the dedication and pioneering effort of all those involved in the original program.

This curriculum is dedicated to the many Ontarians who have given the gift of life through the donation of organs and tissue and to the many others who will in the future.

For more information on the *One Life…Many Gifts* curriculum program please contact the Director of Communications, Trillium Gift of Life Network at 1-800-263-2833 or visit: www.onelifemanygifts.ca

Medical health-care professionals from the field of organ and tissue donation and transplantation and educational advisors were involved in the development and implementation of the *One Life…Many Gifts* project.

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