

WEB DONORS: LOOKING FOR ORGANS ONLINE

Introduction

Focus

With the knowledge that they may die waiting for an organ to become available from traditional sources, many gravely ill Canadians are turning to the Internet to save their own lives. This *News in Review* story looks at the controversial new trend of acquiring organ donations via the Internet.

Did you know . . .

Medical researchers are busy investigating whether new organs can be grown from cells. Early success has led some observers to view this process as a solution to the lack of transplant possibilities.

Their stories combine the heart-wrenching elements of sadness and desperation. She is a 45-year-old single parent who has been going for kidney dialysis three times a week for two years. He comes from a family with a history of kidney failure, and now a kidney transplant is the only thing that will restore his quality of life. She is a 29-year-old whose kidneys failed while she was pregnant with her daughter. Shortly after her daughter's birth, her husband left, and now she needs a kidney transplant if she hopes to see her daughter grow up. All three face the prospect of a five- to 10-year wait on the transplant list. All three may die waiting. In desperate hope, all three have turned to the Internet to try to find a donor who will benevolently give them the organ that will save their lives.

Currently, there are over 4 000 Canadians on the organ transplant list. While close to 2 000 organ transplants will take place in hospitals across Canada this year, more patients will be added to the list, keeping the number too high for most people's comfort. Tragically, almost 200 Canadians will die waiting for an organ transplant this year.

Doctors often say that organ transplantation is a victim of its own success. Since surgeons successfully completed the first kidney transplant in 1954, the art of transplantation has grown steadily. Now kidney transplants—which account for almost three quarters of transplant procedures in Canada—occur alongside liver, lung, heart, and cornea transplants. Surgical procedures have improved, as have anti-rejection drugs, making organ transplantation a viable option for people suffering from conditions like kidney, liver, and heart failure.

Traditionally, the transplant world has relied on the sudden deaths of previously

healthy people for organ donations. So-called “cadaver donations” see the organs of the victim of a severe head trauma (either accidental or natural) donated to needy recipients by the victim's family. Once approval is given by the family of the deceased, doctors proceed to surgically remove the needed organs and distribute them to the people on the transplant list who are the most gravely ill. This approach has been quite successful up until very recently. However, the number of cadaver donations has dropped due to developments in medical science and improved safety devices and standards. In other words, people are more likely to survive head trauma today than 60 years ago because doctors have new strategies and equipment to deal with these injuries. Also, seat belts and air bags are preventing life-threatening injuries that used to occur in car crashes. More people are now wearing helmets while participating in sports like biking, skiing, and snowboarding. Thus, a blessing has become a curse for transplant doctors: with more people surviving head traumas brought on by strokes, aneurisms, hemorrhages, and accidents (an absolute good from the perspective of health professionals) there are fewer cadavers from which to gather organs.

This has led to a surge in what the medical community refers to as “living donors.” In 1995, two thirds of organ donations came from cadavers. Ten years later, over half of all organ donations came from living donors. Doctors have known for a long time that the overwhelming majority of people can live with one kidney. Thus, hypothetically, almost everyone could donate a kidney to someone who has seen one or both of their kidneys fail. However,

Canada's organ donation rate is alarmingly low—falling well behind many other nations, with a donation rate of 13.5 donors per million people in the population.* Almost 2 500 of the 4 000 people on the national transplant list are waiting for a kidney. Imagine living with the knowledge that the waiting list is so long that it could take up to a decade to get a new kidney, and that you could die while waiting for a transplant. Meanwhile, a potential donor could be living just down the street from you.

This situation has prompted many people to bypass the traditional national organ transplant list and seek a donation on their own. The most popular alternative source for obtaining an organ donor: the Internet. One of the leaders in this trend is MatchingDonors.com, a Web site that has registered almost 3 000 donors and has facilitated 19 transplant surgeries. The owners of the site say MatchingDonors.com is an advertising platform for patients desperately seeking an organ donor. Health professionals are concerned that the site approaches the complex issue of organ donation in the same manner as a dating service. Essentially, donors and recipients find each other, correspond for a period of time and then seek medical help in determining if a match has been made. Those in need of a transplant pay MatchingDonors.com US\$295 a month to post their plea for an organ—a fee that patients say is well worth the money if a transplant donor is found.

Health professionals also fear that use of the Internet to solicit organ donations

will lead to the emergence of a capitalist-style organ market. It is illegal in Canada and most other nations to profit from the donation of an organ. The word *donation* promotes the ideal of voluntary giving. It would be grossly malicious for any person to extract money or goods from a desperately ill person, thereby profiting from another's misfortune. In Canada, a donation must be altruistic, or completely unselfish, and should demonstrate a concern for the well-being of another person even if such an action results in one's own suffering. The founders of MatchingDonors.com feel their Web site is a forum for altruistic behaviour on the part of donors and the source of a new lease on life for organ recipients.

If nothing else, the trend of finding organ donors on the Internet has challenged the traditional method of facilitating organ donations. The fact that the organ donor rate has been so low for so long, and that Internet donation initiatives have proven to be very successful, has forced health professionals to consider the ethical validity of online enterprises. Stories dealing with online organ donations have drawn attention to the organ shortage as well as the compelling stories of those in need of an organ. In effect, they have driven people to donate. Perhaps the Internet will be the vehicle by which the organ transplant list is shortened and fewer people will die waiting for organs.

*Canadian Association of Transplantation (www.transplant.ca) and the Canadian Organ Replacement Register (<http://secure.cihi.ca/cihiweb>)

Inquiry

1. List the three statistics indicated in the second paragraph. Which statistic do you think is most compelling? Why?
2. What is the difference between a cadaver donor and a living donor? Why has there been a recent surge in living donors?
3. Why have people turned to the Internet to find an organ donor?
4. What fears do health professionals have about online organ donation?
5. How has online organ donation challenged traditional methods of acquiring organs?

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Video Review

Answer the questions in the spaces provided.

1. What moved Jenny Ode to make the decision to donate a kidney to Mike Fogelman?

2. How did the suicide of a close friend change Jenny Ode's view of life?

3. What is meant by the expression "altruistic donation"?

4. Why did Baruch Tegegne sue the Royal Victoria Hospital in Montreal?

5. Why did Dr. Douglas Keith object to performing a transplant for Tegegne?

6. What do health-care specialists fear about the rise of Internet organ donations?

7. How often does Bruce McLaren go for kidney dialysis? _____
8. Why does Douglas Keith feel it is hard to justify the risks in facilitating donations by strangers?

9. What did Mike Fogelman say he would do if Jenny Ode ever fell on hard times?

10. Do you personally approve or disapprove of the Internet process for organ donation? Explain.

11. Would you consider donating an organ? Under what conditions?

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Organs Wanted!!!

People have gone to extreme lengths to acquire organ donations. Tom Krampitz paid to advertise on two large billboards in his hometown of Houston, Texas, and conducted a number of media interviews to draw attention to his desperate need for a liver donation. The strategy worked, and Krampitz got his new liver. Others have turned to the less expensive option of advertising their need for an organ donation on the Internet. Some have started their own sites (KenNeedsALiver.com and DaddyNeedsALiver.com are two such Web sites) but many others have gone with larger organizations to help them find an organ. For example, Sheryl Wymenga of Welland, Ontario, used the non-profit livingdonorsonline.org to facilitate the donation of her kidney to a 68-year-old man from North Dakota. The success of efforts such as these have prompted others to get into the organ donation business. Two companies have emerged as major players in the organ donation game on the Internet. Bypassing traditional transplant lists, MatchingDonors.com and LifeSharers have, if nothing else, demonstrated the frustration that people in Canada and the United States have felt while waiting for a donor to share the gift of life.

MatchingDonors.com was started in 2004 by Paul Dooley and Dr. Jeremiah Lowney. The two had grown frustrated with the pain people were forced to endure while they waited patiently on the organ transplant list. Their idea was to create an advertising platform for recipients and donors so that a free and open exchange could take place. Now, potential recipients agree to pay a

monthly fee of US\$295 to post their plea for an organ. Potential donors navigate the site free of charge looking for someone to whom they would like to donate an organ. When an online match is found, the donor and the recipient are on their own to see if a medical match has been made and to find a transplant centre to perform the procedure. Critics of the scheme worry that MatchingDonors.com makes no effort to ensure that the organ donations are truly altruistic. Dooley and Lowney make no apologies for this. They count on their clients to guarantee that donations are truly altruistic.

In October 2004, just 10 months after opening their site, MatchingDonors.com facilitated their first organ transplant. Bob Hickey of Colorado bypassed the U.S. national donors list by posting an ad on the Web site. Rob Smitty of Chattanooga, Tennessee, responded to the posting, and the transplant operation was scheduled to occur at Presbyterian-St. Luke's Medical Centre in Denver, Colorado. The initial surgery was called off when the surgeon, Igal Kam, learned that Hickey had paid Smitty \$4 500 prior to the operation. Kam was concerned that Hickey was buying an organ from Smitty, an action that is illegal in the United States. After a brief inquiry, Kam agreed to perform the operation, citing the fact that Hickey did not pay anything beyond Smitty's travel expenses and lost wages. The transplant is believed to be one of the first to be facilitated over the Internet by a for-profit company.

Another Internet donation scheme that has attracted attention is called LifeSharers. The goal of LifeSharers is

to expand the donor pool by offering would-be living donors an incentive: agree to donate your organs and LifeSharers will guarantee that you will receive an organ donation if you ever need one. Here is how it works: a person registers on the LifeSharers Web site and agrees to donate their organs. If a would-be donor ever finds themselves in the unfortunate situation of needing an organ, LifeSharers will find a donor from within their group. The founders of the site believe that a person who is seeking an organ donation should also be willing to donate an organ. Over 3 000 people have bought into the idea and are currently listed in the LifeSharers database.

The emergence of online organ donation has sparked an international debate regarding the ethics of donating

organs via the Internet. Advocates and adversaries continue to plead their cases, with no side delivering a knock-out punch to date. In the meantime, some health groups are finding other creative ways of attracting donors. The British Columbia Transplant Society has recruited 43 kidney donors to take part in a project where altruistic donors anonymously give their kidneys to needy recipients. Doctors in Vancouver have scheduled the first 10 kidney transplants of the project and plan to expand the initiative in the future. Perhaps the future of organ transplantation will combine the best of the traditional system with the innovative approaches emerging from Internet donor sites and thoughtful initiatives like the one put forward by the B.C. Transplant Society.

Questions

1. How are people bypassing traditional channels and acquiring organ donations on their own?

2. Why has MatchingDonors.com been so successful?

3. Do you agree with the philosophy of LifeSharers? Should someone who needs an organ also demonstrate a willingness to donate an organ?

4. What shape do you think organ donation will take in the future?

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Organ Donation and Medical Ethics

Definition

Ethicists are people who are concerned with morality and human conduct. They try to determine what is the correct thing to do.

On the surface, the idea of organ donation speaks to the merits of altruism, generosity, and benevolence. But, once ethicists dig a little deeper, it becomes clear that safeguards need to be in place to protect society from questionable and possibly immoral behaviour.

Ethical Consideration #1: When is a dead person dead?

A common source of organ donations is the body of someone who has just died. These are called cadaver donations. However, transplant doctors do not acquire organs from just any corpse. The person who dies needs to have been reasonably healthy prior to the time of death, so suitable cadavers for organ donation have usually suffered a severe head trauma either brought on by a stroke, a brain aneurysm, or a cerebral hemorrhage. This is the case in almost 50 per cent of cadaver donations in Canada. The other half of cadaver donations come from accident victims, with almost a quarter of this group representing the victims of motor-vehicle accidents (source: www.transplant.ca).

Ethical problems emerge with regard to cadaver donations when one digs a little deeper into the medical definition of death. Medical ethicists ask the question: when is a person dead? Let's say a person suffers a brain aneurysm and is rushed to the hospital. Doctors and nurses work diligently to help the person regain consciousness but to no avail. The

patient continues to breathe with the help of a ventilator, and the heart continues to pump; however, the patient is declared "brain-dead." The doctor approaches the family to deliver the bad news. Brain-death is an irreversible condition; there has been so much trauma suffered that the patient has no chance of recovery. There have been no recorded instances of a person recovering after being declared brain-dead. But is a patient really dead if the heart is still pumping? Even though it is the ventilator that is artificially keeping this person alive, is there really nothing happening in the mind of the patient? Has a person who is still breathing and whose heart is still beating really left this world? Is it ethical to prepare to harvest the organs if the patient is still breathing? Or should doctors keep the patient on the ventilator and wait (even if it takes years) for the patient to die naturally?

In essence, medical professionals seeking organ donations approach the families to ask their permission to "pull the plug" on the ventilator so that they can harvest the organs. Some people wonder if this does not amount to killing the person to get to their organs. Others claim that, for all intents and purposes, the person is dead and will never come out of the brain-dead condition. Therefore it is more compassionate to release the patient from the artificial life that exists only because of the ventilator.

For Consideration

What do you think? Should doctors have the right to harvest the organs of someone who is brain-dead? Please explain your answer with reference to the information provided.

Ethical Consideration #2: Should I be able to choose who gets my organs?

Most live organ donations involve a needy recipient and a compassionate family member or friend who agrees to give up an organ to help someone they love. In these cases, there is an element of choice involved—the family member or friend chooses to give an organ to someone they care about. This is called directed donation. However, there is a growing trend of altruistic donations where a stranger donates to another stranger. For the most part, altruistic donations are anonymous. For instance, a person might contact the Kidney Foundation and offer to donate a kidney. The Kidney Foundation would then facilitate the donation. The recipient would simply be informed of the person's age and sex. They would not be told the person's name, address, or occupation. But what if the donor wants to donate to a certain kind of person? This question became increasingly relevant in 1990 when two Florida parents agreed to donate the heart, liver, kidneys, and pancreas of their recently deceased son as long as the organs went to white recipients. Their son was a former member of the Ku Klux Klan, so

they directed their donation away from ethnic groups that their son hated in order to honour his beliefs. Shockingly, the hospital agreed. Later, the state of Florida changed the law so that this kind of thing would not be allowed to happen again.

On the other side of the issue, should a recipient be able to screen donors beyond issues that deal with basic health concerns? For instance, if a murderer, pedophile, or rapist decides to donate an organ, does the recipient have a right to know this information? Would you want the kidney of a pedophile put into your body? What if you were the victim of a pedophile? Here is another example: what if the liver of a young woman killed in a car accident by a drunk driver was transplanted into an alcoholic who had destroyed his liver after years of alcohol abuse?

However, for most people who are suffering from organ failure, these questions are totally irrelevant. They would gladly accept a kidney from any healthy donor because the new organ would relieve them of a great deal of their suffering. Deep down, organ recipients know that the organ does not make the person.

For Consideration

Should organ donors be able to choose the kind of person who gets their organs?

Should an organ recipient be informed of non-medical information like the past history of the donor who is giving them a new organ? Is this a relevant question?

Please explain your answers with reference to the information provided.

Ethical Consideration #3: Should I be paid for giving my organs away?

There are strict laws in Canada that prevent a person from being paid for their organs. This prevents people from selling their organs for profit or extorting people who are suffering from dire illness into paying exorbitant prices for the organs that will save their lives. In principle, organs should be donated. The donation should be an act of pure altruism with the donor expecting nothing in return.

However, medical ethicists have deemed it appropriate to compensate donors for travel and out-of-pocket expenses brought on by the donation as well as lost wages during the donation process. So why not go to the next step and allow for organ trade? Shouldn't people be allowed to sell their organs if they choose to? Don't the benefits (the saving of a life) outweigh the costs (a financial gain for the donor)? Certainly,

desperate kidney patients seeking freedom from dialysis and suffering would be willing to pay top dollar for a new kidney.

Take the case of Albery da Silva, a 38-year-old man from Brazil who received US\$10 000 for one of his kidneys in an illegal organ trafficking deal. The transaction was administered by two brokers from Israel who have since gone to prison. They charged an anonymous American woman US\$150 000 for da Silva's kidney. Despite the fact that da Silva made only a fraction of the price charged, he was ecstatic to find himself US\$10 000 richer; a sum that would take him over seven years to earn while working at his low paying job in Brazil. Shouldn't da Silva have the right to sell his kidney if he wants to, or is organ trafficking the moral equivalent of prostitution wherein a person sells part of their body for profit?

For Consideration

Should a person have the right to sell their organs to the highest bidder? Why do you think Canadian lawmakers have deemed this practice to be illegal? Should the laws be changed? Please explain your answers with reference to the information provided.

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When Your Kidneys Fail

Further Research

For more information on your kidneys go to www.kidney.ca.

Your kidneys perform a number of essential functions that keep you healthy. They are about the size of a fist and rest at the lower end of your rib cage, with one kidney aligned on each side of your spine. Blood flowing into your kidneys is filtered, with the clean blood flowing back into your system and the unwanted fluids (the residue of the filtering process) moving into your bladder in the form of urine. Doctors estimate that your kidneys filter about 200 litres of fluid per day, with two litres of urine heading for the bladder and eventually out of the body. The kidneys also help to maintain a chemical balance of salt, potassium, and acid in your system. They foster the production of a hormone called erythropoietin, or EPO, that aids in the production of red blood cells. But what happens when your kidneys stop functioning properly? The results can be dire. Since unwanted fluids are not being eliminated by way of urination, toxins build up in your system, resulting in symptoms like nausea, fatigue, and loss of appetite.

In some cases, the kidneys of a person fail. Doctors call this renal failure. A person in renal failure has three options. First, they can use an artificial kidney machine to perform the functions that the failed kidneys are unable to carry out. This process is called hemodialysis. This option involves the use of plastic tubing, inserted through blood vessels in the arms or

legs, to flush the system of impurities that have built up in a person's system. Hemodialysis can be done at home or at dialysis clinic, with the process taking between three and five hours in most cases. The second treatment is called peritoneal dialysis. This form of dialysis involves the surgical insertion of a catheter into the person's abdomen. Dialysis fluid is then injected through the catheter to clean the blood in the area around the abdomen known as the peritoneal cavity. The dialysis fluid performs the function of cleaning the blood that the kidneys are unable to do. Later, the dialysis fluid is flushed out of the system through the catheter and replaced by new fluid. This process can take place at home but does involve a steady routine of replacing and draining dialysis fluid. Finally, a person suffering from kidney failure can replace a kidney through kidney transplant surgery. Two problems accompany this option. First, the waiting list for a kidney is long. Second, people who receive a kidney from a donor have to take a steady regimen of anti-rejection drugs for the rest of their lives. This is because the body naturally senses that something foreign has been introduced. The drugs help the body to accept the new organ. However, most patients would gladly deal with the anti-rejection drugs for life in place of dialysis and the suffering brought on by kidney failure.

Analysis

1. Describe the functions of the kidneys.
2. What three options are available for a person who is suffering from renal failure?

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Activity: The Presumed Consent Debate

Is presumed consent the solution to the organ shortage?

One proposed solution to the organ shortage is a scheme referred to as “presumed consent.” This strategy is based on the assumption that everyone is a willing organ donor unless they let the government know that they do not want to donate their organs. To opt out of the plan, people must fill out a form and submit it to provincial health officials to keep doctors from harvesting their organs upon their death. Families can also make the choice to opt out of the plan at the time of the death of a loved one. Currently, no Canadian jurisdiction employs the “presumed consent” scheme. Nonetheless, the plan has been successful in nations like Spain. Since introducing “presumed consent,” Spain has seen the organ donation rate climb as high as 32 donations per million people in the population—more than double the donation rate in Canada.

Your Task

Prepare a debate surrounding the presumed consent issue. Use the information included in this *News in Review* feature to help build your case.

Resolution

Be it resolved that the provincial governments of Canada should introduce legislation that presumes that all citizens of the country are willing to donate their organs to someone in need unless they formally object to organ donation and make the government aware of this fact in writing.

Pros — Argue in favour of the resolution. Cite the organ shortage and the overwhelming benefits of such a program. In essence, argue that presumed consent would eliminate the organ shortage in Canada.

Cons — Argue against the resolution. Demonstrate that there are options other than compelling all citizens to give up their organs upon death. Argue that the element of choice is a basic right and that the government should not be “presuming” anything when it comes to your body (whether you are alive or dead).

Debate structure

Teacher — Read the resolution and referee the debate.

Pros — Opening statement

Cons — Opening statement

Pros — Respond to the Cons’ opening statement.

Cons — Respond to the Pros’ opening statement.

Pros/Cons — Freely debate, each in turn

Pros — Closing statement

Cons — Closing statement