

IAB News

The Newsletter of the International Association of Bioethics

Issue No. 20

Mar 2008

Contents

Contents

| | |
|---|----|
| Organ Transplantation <i>Indian Scenario</i> <u>J. Azariah</u> | 2 |
| Ten Years After the Organ Transplant Act: <i>The Current Situation in Japan</i> <u>M. Fujita, et al.</u> | 5 |
| Brain Death and Organ Transplant Face the Intractable Traditional View On Death in Japan <u>N. Tanida</u> | 5 |
| Bioethics as a Tool for the Practice of Organ and Tissue Donation <u>B.DA Roza, et al.</u> | 7 |
| Issues in Organ Transplantation: <i>News from the Netherlands</i> <u>M. Hilhorst, et al.</u> | 13 |
| Organ Donation And The Family Veto <u>M. Wilkinson</u> | 16 |
| Part of My Liver <u>J. Dwyer</u> | 16 |

This issue has 19 pages

Earth Image from NASA

Editors:

ANGUS DAWSON
INEZ DE BEAUFORT
JAYAPAL AZARIAH

a.j.dawson@keele.ac.uk
i.debeaufort@erasmusmc.nl
jazariah@yahoo.com

Layout:

DAWN BENIGNO

The International Association of Bioethics Newsletter would like to hear from you.

If you have comments, suggestions, or if you would like to contribute to the next issue, or have events announced, please contact any of the IAB News editors.

ISSN 1028-5032



9 771028 1503002

Message from the Editors

We are pleased to welcome you to the latest edition of the IAB newsletter. We have decided to experiment with a different format as a means of better fulfilling the aims of the newsletter. We will devote most of each newsletter to a particular topic in bioethics and seek short articles describing situations in different countries, recent policy changes, or new perspectives upon the relevant ethical issues. Articles should be short discussions from any bioethical perspective and accessible to anyone across the world.

We hope that this will provide a new focus for the newsletter and encourage information exchange and generate debate. The theme of this newsletter is 'ethical issues in organ transplantation'. The next newsletter will focus on issues relating to '**informed consent**', and the one after that '**global justice**'.

We invite short articles on these themes that will be of interest to all IAB members. If you would like to submit something, we suggest that you discuss this with one of the editors as soon as possible. We would also like to encourage you all to engage with the articles previously published in the newsletter, through the submission of short letters or comments. These will appear in subsequent newsletters. We would also welcome suggestions for possible future themes. Our deadline for submissions for the next newsletter will be on the **1st June 2008**.

Jayapal Azariah

Inez de Beaufort

Angus Dawson

Organ Transplantation: Indian Scenario

By Jayapal Azariah

Introduction

Ethics behind organ transplant is governed by many factors such as the desire to live longer as a result of replacement of defective organ with a healthy one, the lure of money for the agents and others who are involved in the deal and as well as the availability of healthy organs. The economics of demand-supply controls all the factors connected with organ transplantation. Such commercial prospects have brought in brokers to lure the unsuspecting victims to sell their kidney for money. The present situation of scarcity of human organs for transplantation has introduced many serious bioethical issues. The brokers bring in unrelated donors and a deal is materialized. As a result India has become the 'great organ bazaar' (market). The whole business has come to be known as the 'organ trade'. The phenomenon of 'Medical Tourism' is a modern way of carrying out organ transplant. A authentic tour can be organized for medical treatment. India has become one such nodal center for medical tourism. Private Indian hospitals can offer high-class health care at a cheaper cost and without much waiting. The Government has also introduced 'medical visa'. Such tours have been misused and the government has now brought in restriction. The practice of 'kidney marriages' is also reported where in a wealthy foreigner marries a poor Indian girl. Because she is his legal wife she can donate her kidney. After a few months the wealthy man with a new kidney returns to his own country with a promise of sending visa for his wife to join him. The visa never arrives.

The Act of 1994

The business of organ trade, with special reference to kidney, was flourishing since early 1980. As a result the Government of India brought about a legislative instrument to arrest the practice of illegal trade in human organs. This act is commonly designated as the Transplantation of Human Organs Act 1994. The Act allows transplantation only on grounds of compassion and a special committee screens

the motive of organ donation, either due to compassion or due to monetary or other material gain. It also permits organ transplant only between close relative. The main essence of this Act is twofold. (i) Removal of organ only for therapeutic purposes and (ii) to arrest commercial dealings in the organ transplant. Moreover, the Act provides a legal framework to prevent any illegal practice in kidney donation. The Act has made provisions for the institution of two governing committees. They are (i) a State Transplantation Authorization committee (STAC) to scrutiny of all such applications for organ transplant. (*Mudur 2004 and Sangameswaran, 2007*). The other committee is the Appropriate Authority which oversees the qualifications of a hospital to perform organ transplant. Such hospitals are required to register with the Authority.

Therefore, it is required by law for a hospital to register to "conduct or associate with or help in, the removal, storage or transplantation of any human organ". Secondly, the police have no investigatory powers. Such powers are vested with the Department of Health. The Director of Medical Services can lead a team of officials to inquire into kidney transplantations especially those involving live or unrelated donors. Thirdly, the Act endorses the functioning of the Authorization Committee under the purview of the Directorate of the Medical Education of the State. Fourthly, the donor should not be below the age of 18, even if the donor is a close relative. The entire weight of the Act is to prevent the commodification of a human organ through intermediary agents. The Appropriate Authority has full powers to cancel the registration of a hospital if found to violate the rules and regulations of the Act.

Even if a donor gives a written permission for the removal of his /her organ for transplantation to an unrelated recipient, the said organ can not be removed without the prior approval of the committee. As per this legislation the donor and the recipient should submit their applications and the committee should hold an inquiry and only after satisfying itself that the applicants had complied with all the requirements of the Act and Rules, should it authorize the removal and transplantation of human organs. If there is any

violation then the Authority will issue a show cause notice to the erring hospital. Then on the basis of the notice given by the Authority the hospital has to respond giving reasons for their action and provide all documentary evidences. If the Appropriate Authority is not satisfied with the response then it may without prejudice to any criminal action it may suspend the registration of the hospital for such period that it deems fit. In extreme cases it can also cancel registration of a hospital.

The connections

An unethical practice of exploiting of has turned the noble medical profession in to a business. The exploitation of marginalized people makes it difficult to understand the ethics behind such a practice. A connection can be established between anephrologists and an agent (a blood donor) of organ procurement who in turn lure their victim to sell their organs (*Reporter, 2001*). In a recent case a woman was made to part with her kidney by submitting forged documents. She was promised a sum of Rs. 150,000 but was paid Rs. 30,000 only. The agent gets a commission on the deal.

The Authorization Committee cleared about 1936 applications in three years. The authorization committee of Karnataka State in India cleared about 192 donor requests without rejecting any application filed during 1999 and 222 applications in 2000 and about 160 applications in 2001 (*Website, 2007*). Sanctioning transplantation for all application filed has raised serious doubts about the integrity of the Committee members. What is more disturbing is that the Bioethical Law keepers themselves are involved in the unethical practice of organ trade and transplant. In order to check the corrupt practices of the senior doctors, the Government has included three senior police officers from three different regions like Chennai, Madurai and Coimbatore in Tamil Nadu as members of the authorization Committee with an objective of preventing commercial "kidney racket" dealings in human organs! (*Sangameswaran, 2007*). It remains to be seen how efficient the new inclusion will be in terms of corruption mitigation! Will it work? Recently, a survey revealed that 81 per cent of Non-

Resident-Indians have paid bride in India (*Correspondent, 2007 b*).

New Governance

Recently the Governance has become tougher (*Kannan, 2007 a*). Thirteen well reputed hospitals were found to violate the rule and regulation with irregular documentation on donors and recipients of human organs. Such a situation has led to the cancellation /suspension or non renewal of licenses of the 13 hospital. Two hospitals were found guilty of forging organ transplantation orders. License granted to M.R. Hospital in Chennai with respect to organ transplantation was cancelled. License granted to Aswini Soundarya Nursing Home, also in Chennai, was not renewed. Out of the 48 hospitals that were authorized to perform organ transplantation, currently only about 33 hospitals have government clearance to remove and transplant an organ. (*Kannan, 2007 b*).

Hospitals that have violated the Act (*Kannan, 2007 a*):

1. Vedanayagam Hospital in Coimbatore
2. PSG Hospital, Coimbatore
3. Kovai Medical Centre, Coimbatore
4. G. Kupuswamy Naidu Hospital, Coimbatore
5. Kavery Meidcal Centre Trichy
6. Ramakrishna Nursing Home, Erode
7. Galaxy Hospital, Tirunelveli.
8. Devaki Hospital, Chennai
9. Chennai Transplant Centre, Madras Medical Mission, Chennai
10. ABC Hosptial, Chennai
11. Chennai Kaliappa Hospital, Chennai
12. Apollo Speciality Hospital, Madurai
13. Meenakshi Medical Mission, Madurai

There is a remarkable decline in the number of applications received and the number transplants done through unrelated donors, during January to June. (*Correspondent, 2007 a*).

e-Governance

Currently there is transparency. The Government has placed all information in its

newly opened website which provides all information about transplants. All Information will be posted on www.tnhealth.org which will also serve as online Registry, providing details on the number of applications received and the number cases approved or rejected. The Government also plans more comprehensive measure to re-examine of the transplantation act to plug the loopholes (*Kannan, 2007 b*). Under the present Act the decision of the Committee whether it has rejected or approved the request of an organ donor applicant who is not related to the patient, will be communicated only to the Hospital concerned. And reasons for not approving the request will not be provided. Under this new scheme the applicants will have more details about their case and can know the decision of the Committee as soon as the Committee's proceedings are over. Reasons for rejecting live unrelated donors will be posted online which may help others to submit a clear documented application. It is hoped that such a transparency may make the operation of the kidney sale racket ineffective and make the system more accountable. Under this new venture for the first time, the verdict of the Authorization Committee will be made public. Details regarding the names of the hospital, patient and donor, result of the interview and remarks will be posted on the web. All the seven applications cleared on June 7, 2007 were posted on the web (*Kannan, 2007 c*). The safeguard is that the date of surgery has to be informed to the Directorate of Medical Education and the donor has to be produced for medical check up one to three months after surgery to address of chronic neglect of persons who are duped into selling their kidney (*Kannan, 2007 c*).

References

Correspondent, Special 2007 a ***Taking the message of organ donation to a larger audience.*** *The Hindu* 08.06.07 p. 8.

Correspondent, Special 2007 b ***91 per cent of NRIs paid bribe in India: Survey.*** *The Hindu* 12.07.07 p. 10

Kannan, Ramya, 2007 a ***Transplantation licenses withdrawn: Two Chennai hospitals found quietly of forging organ transplantation orders.*** *The Hindu* 13.04.07 p. 1

Kannan, Ramya, 2007 b ***Organ Donation authorization Panel's Decision likely to go online.*** *The Hindu* 19.06.07 p. 5

Kannan, Ramya, 2007 c **Organ transplantation Panel's verdict on web.** *The Hindu* 03.06.07 p. 10

Mudur, G., 2004 **Kidney trade arrest exposes loopholes in India's transplant laws.** *British Medical Journal* 328: 246

Reporter, Staff, 2001 **Gang trading in Kidneys busted.** *The Hindu* 19th May p. 6

Sangameswaran, K.T., 2007 **3 Police officers nominated to kidney authorization panels.** *The Hindu* 03.05.07 p.4

Website 2007 **Karnataka's unabating kidney trade.** *Frontline* Volume 18. March- April 2002
<http://www.hindupmmet.com/fline/fl1807/19070610/htm>□

Ten Years After the Organ Transplant Act: The Current Situation in Japan

By Misao Fujita, Satoshi Kodama & Akira Akabayashi

It has been ten years since the Organ Transplant Act was enacted in Japan in 1997. A variety of issues related to organ transplantation have developed since then and have generated much debate nationwide. In October 2006 the first case of organ trading was uncovered in Japan. A man who received a living donor kidney transplant and his common-law wife were arrested on suspicion of violating the Organ Transplant Act. It was reported that her female friend falsely described herself as the man's sister-in-law, donated a kidney, and received 300,000 Japanese yen in cash and a brand new car after the successful operation. In December, both suspects were sentenced to a year in prison with 3 years probation, and the donor was also fined. The doctor in charge of the transplant was not indicted because he had had no knowledge that an illegal trade was taking place.

However, an internal investigation into the scandal by the hospital revealed a different problem. Several doctors, including the surgeon involved in the trade scandal, had been using kidneys removed due to disease (cancer, ureterostenosis, aneurysm, and nephrosis) as transplants for other patients. Eventually it became clear that this "renal transplant with disease" had been performed on 42 patients in 5 hospitals. The media reported that signed consent forms with explanations about the procedure could not be located for almost any of

the patients. Nor had anyone asked the ethics committee to review the practice, even though the effectiveness and medical validity of organ exenteration are as yet unproven. The hospital was criticized by the media for ethical lapses in its use of the procedure. Accordingly, the Ministry of Health, Labour and Welfare revised the procedural guidelines for the Organ Transplant Act and the Japan Society for Transplantation publicly announced a new ethics policy requiring strict regulation of living organ transplants.

The difficult transplantation issues Japan struggles with ten years after the implementation of the Organ Transplant Act are rooted in the scarcity of transplantable organs. As of November 2007, organs from only 62 brain-dead donors have been made available. The scarcity may be due to some regulations in the current Organ Transplant Act, such as requiring written consent from both the patient and the family and limiting organ donation to people 15 years of age or older. Two revision bills have been submitted to the Diet that would ease the regulations and thereby increase the number of organs obtained from patients with brain death. However, enactment of the bill has been slow in coming, and no real action has yet been taken. Improving the organ transplant system is an urgent issue, and will be the key to progress in organ transplant in Japan over the next 10 years.□

Brain Death and Organ Transplant Face the Intractable Traditional View on Death in Japan

By Noritoshi Tanida

The 16th of October, 2007 was a memorial day for the Organ Transplant Law (OTL). This law came in to effect on this day, 10 years ago. There were several ceremonies and meetings by pro and cons groups regarding the brain death and organ transplant (1). In this article I shall describe the current situation of organ transplants in Japan. Thereafter, I shall also discuss the traditional Japanese view on death and its implication toward the brain death and organ transplant.

The concept of OTL was principally the same as that in other countries except that the authentic donor card with explicit written consent by the

brain dead is mandatory and a patient older than 15 years can donate his/her organs. In addition, "brain death is a human death" only when an organ transplant is on schedule. During the last 10 years, a total of 61 brain deaths were diagnosed for organ transplants according to OTL. Yet, such a small number of brain deaths and organ transplants have frustrated the waiting patients and their advocates. Furthermore, although brain death may be diagnosed in children older than 6 years, young children cannot receive organs from the brain dead because of the age limit set at over 15 years of the donor age. Domestically, waiting patients and their advocates proclaim modification of OTL so that an organ transplant from the brain dead can be carried out in children and organs may be used from the brain dead based on the consent given by his or her family. However, cons groups still try to ban organ transplants from the brain dead mainly for two reasons, 1) brain death is not a death, because the heart is beating and the body is warm, 2) when the idea of brain death is accepted, the doctor will abandon treatment of the patient who can recover by further treatment. Other moral or ethical reasoning against the brain death and organ transplant, e.g., "being natural for life," is not an assembling factor for cons groups.

In OTL, there is a Clause which says that OTL should be revised after a period of 3 years. Hence, OTL has undergone modification in the past 3 years period in practice. Then, in 2004, the two ruling parties sent different bills for modification of OTL. The Liberal Democratic Party (LDP) claims that the brain death is a human death (beside so-called cardiac death), a donor's age may be limitless, and organs may be removed by family's consent unless the brain dead has expressed unwillingness of donation. The Komei Party (KP), who are disciples of one of the Buddhist sects, claims that only the age limit of organ donation may be changed at over 12 years of age. The consequence due to such inconsistent attitudes in the ruling parties is obvious, i.e., these bills have been left untouched and kept "under discussion" in every term of the parliament since the time of proposals. The proposed bills by the LDP and KP have explained the current opinions regarding the brain death and organ transplant. The

atmosphere in the parliament represents an awkward attitude of the Japanese society towards OTL modification. In the meantime, there are many patients, young and adults, who go abroad for procurement of organs.

Why do Japanese people resist accepting brain death? I think it is because of the way of thinking seated deep inside of people's consciousness. In Japan, the traditional notion on death was separation of the body and soul. Japanese people did not think that the cessation of heart-beat and respiration was an indication of the death of the person. They made a '*mogari* or *arakino-miya*, a special palace to place the body and they prayed for the return of the soul or the revival of that person after many days, even years for ex-powerful rulers. Naturally they attached importance to the body. More than one thousand years ago, the government enforced cremation as a formal way when Buddhism was introduced.. However, people harshly resisted to cremate a dead body, and it was one of the reasons why Japanese people attacked Buddhism during the period of Meiji Modernization one hundred and fifty years ago.

I thought this notion on death was only seen in history. But, I have been forced to change my understanding. Recently, Japanese police has made murder charges to several doctors who withdrew a respirator from the dead person; dead according to medical science (2). The latest case was symbolic in this matter (3). In this case, the doctor stopped a respirator from a terminally ill patient and ascertained the death of the patient. Of course respiration of the patient did not resume, hence the doctor did not re-introduce a respirator and declared the death of the patient. Astonishingly, this doctor was charged as a murderer by police. The act of Japanese police cannot be understood from a view of the rational person. Japanese police think that the complete stop of respiration or the physical death is not a death. It is surprising to note that their notion on death is still that of people who lived thousand years ago. Presumably, hospital is a kind of *arakino-miya*, and hence, artificial respiration and other cardiopulmonary resuscitation techniques are only modern tools for praying the revival of a dead person or the return of the soul of

contemporary people. Even, medical science has given Japanese people modern equipments to prolong the dying process so that people can maintain the traditional view of death. According to a media report, a number of "clinically brain dead" children who were given medical care for longer than one month is about 60 in 522 Japanese hospitals during August to October, 2007 (4). The article mentions that not only family members but also doctors who take care of these children cannot accept the situation. Mass media deal with these stories as admirable tales. Thus, many Japanese do not accept the brain death as they do not think that the stopping of the heart-beating and respiration is death.

While people do not accept death, a number of ethical problems are increasing. Perhaps, the biggest issue in relation to other countries is organ transplants which were carried out in abroad. On the one hand, Japanese people and mass media consider going to developed countries for organ procurement is a brave admirable tale and support the patient and family to raise money for the expenses. On the other hand, they criticize going to developing countries for organ procurement as it is considered as organ-buying. Recently, Japanese Ministry of Health, Labour and Welfare ordered health professionals to stick to OTL which prohibits organ selling and buying. This order came out after the case of kidney selling and buying was disclosed and those concerned were sent to jail. Its consequence was disastrous for the patients who received organs in developing countries, because Japanese doctors cannot see these patients who did "illegal transplants" in developing countries (5). Thus, these patients lose their means of livelihood, whereas those received organs in developed countries are kept under medical care by the national insurance plan as usual.

What can be or should be done in the current situation? It may be certain that introduction of a rational view to irrational people is almost impossible even with regard to death. The attitude of mass media is, by all means, the same as ordinary people who want an eternal life. Advance in medical science has only exacerbated the attitude of people to reject death. Ethical voice is so feeble, because there

are many people who keep against the idea of brain death inside ethical organizations. In USA, naive unrealistic expectations on the part of patients and families have been rectified by the law society (6). However, the Japanese law society has ever been dealing with medical cases only to increase naïve unrealistic expectations of people. Thus, I must express a pessimistic view that the irrational situation regarding the brain death and organ transplant last for ever in Japan. Perhaps, only hope may be pressure from overseas to the Japanese society, banning Japanese patients from procurement of organs in their own countries for example. Otherwise, Japanese people may not awake to their situation and irrationality.

References

- (1) Yomiuri-Shinbun. October 8, 2007.
- (2) Tanida N. *Kanwa-Kea* 2006; 16: 244-247.
- (3) Nishinohon-Shinbun. May 23, 2007.
- (4) Mainichi-Shinbun. October 12, 2007.
- (5) Tokyo-Shinbun September 9, 2007.
- (6) Annas GJ. *N Engl J Med* 2005; 352:1710-1715 □

Bioethics as a Tool for the Practice of Organ and Tissue Donation

By Bartira De Aguiar Roza & Janine Schirmer

During almost 30 years, between 1968 and 1997, a period named "heroic and romantic", the practice of transplantation was little regulated (normally, there were loco-regional regulations), and also developed with a great deal of informality as regards receivers' application, organ removal and distribution criteria of organs obtained. The approval of Law no 9,434 from February 4th 1997, which concerns the removal of organs, tissues and other human body parts for the purpose of transplantation and treatment, created legal conditions for a more egalitarian system of access to this type of treatment. This legislation, among other aspects, foresaw the presumed donation, that is, all individuals are donors, except for those who stated on their Brazilian ID card or on the Brazilian Driver's License that they were non-organ and tissue donors, a statement that could be reformulated at any moment. The negative impact cause by this law was one of the factors that led to the publication of a Brazilian Provisional Measure,

which transferred the decision about donation to the families, without the need for a record on personal documents. The Provisional Measure became Law no 10,211 in March of 2001, introducing the National Registry of Donors, where people could state they were donors. This Law also established that, in case of violent death, the donors will be a priority for autopsy at the Institute of Forensic Medicine. Ethics implies individual option in the active choice. It requires the person's strict adherence to values, principles and the morals; and it is connected to the notion of individual autonomy. It aims at the human being's inner world; it asks for personal convictions that cannot be imposed by outer forces; it demands free, conscious acceptance of the norms. Professionals who work with transplantation in Brazil certainly need space to discuss their moral values and virtues in order to seek ethical competence. Apart from the prioritization in the Brazilian sanitary context, one of the commitments that must be expected from the State is an adequate legislation, followed by relevant sanitary infrastructure that promotes and facilitates the control of a whole new National Transplant System. Besides, even though donation represents a morally good, altruistic social conduct, one may infer that it has not been incorporated into the social morals due to several reasons, such as the discredit regarding the workings and structure of the healthcare system, fund allocation, relation of trust between healthcare professionals and patients, equal and just access, donor/receiver confidentiality, free informed consent, respect for autonomy, protection of life, and the recent, innovative character of this therapeutic possibility, still under development. We believe this is an ethical discussion, as it deals with values, principles and norms that serve as the basis for human behavior. The basis for correct and fair conduct, supported by the responsibility for one's actions, such as not killing. To make an ethical decision, apart from the existence of alternatives for actions, the freedom to choose and act must be given to the ethical individual, according to the decision and alternative chosen by him/her. When there is only one alternative to choose from, or when one can only act according to certain alternative, the action cannot be judged as ethical.

The history of transplantation in the world is certainly one of success, due to its undeniable advance in such short period of time, and undoubtedly marked by countless attempts, achievements, losses and disappointments.

Thus, after studies carried out in France in 1959, which described for the first time the clinical picture of brain death, the University of Harvard published, in 1968, one of the first works establishing criteria for its diagnosis, in this way creating the corpse donor character.(1)

Currently, the term deceased or dead donor seems to be more adequate and its use was promoted by the World Health Organization WHO in the World Health Assemblies of 1987, 1989, and 1990.(2)

In Brazil, organ transplantation began in the 1960's, but this activity gained importance after 15 years with the creation and development of surgical techniques, support equipment, methods for histocompatibility determination between donor and receiver, and, finally, immunosuppressive drugs. Eventually, these procedures spread among hospitals and other health institutions, increasing the need for a donation and organ transplantation regulation.(3)

During almost 30 years, between 1968 and 1997, a period named "heroic and romantic", the practice of transplantation was little regulated (normally, there were loco-regional regulations), and also developed with a great deal of informality as regards receivers' application, organ removal and distribution criteria of organs obtained.(4)

The regulation of brain death (BD) diagnosis in Brazil only occurred in 1991, through the Federal Council of Medicine.(5)

The approval of Law no 9,434 from February 4th 1997, which concerns the removal of organs, tissues and other human body parts for the purpose of transplantation and treatment, created legal conditions for a more egalitarian system of access to this type of treatment.

Decree no. 2,268 from June of 1997 regulated Law no 9,434 and created the National Transplant System, responsible for the infrastructure of BD case notification, as well as the organ and tissue procurement and distribution, which is named waitlist, the waiting list of patients who need an organ for transplant.(6, 7)

This legislation, among other aspects, foresaw the presumed donation, that is, all individuals are donors, except for those who stated on their Brazilian ID card or on the Brazilian Driver's License that they were non-organ and tissue donors, a statement that could be reformulated at any moment.

The negative impact caused by this law was one of the factors that led to the publication of a Brazilian Provisional Measure, which transferred the decision about donation to the families, without the need for a record on personal documents. The Provisional Measure became Law no 10,211 in March of 2001, introducing the National Registry of Donors, where people could state they were donors. This Law also established that, in case of violent death, the donors will be a priority for autopsy at the Institute of Forensic Medicine.(8)

Furthermore, the new Law established that, for non-relative donors, the donation must be authorized by the judicial system.

Despite several legal attempts, the supply of organs from deceased donors does not meet the demand in practically all the countries where transplants are performed.(9, 10)

It can be observed that an increase in the donors' rates depends on seeing beyond the technical matters concerning the organ and tissue donation process, as some countries have been doing. They have been working on this process systematically for a long time, incorporating the social approach and the ethical perspective, based on family volunteering and respect for the potential donors' right to autonomy.(11)

This view needs to be an integral part of those who dream of having, in this process, the certainty of performing work that is just and benefits the community.(11)

Studies carried out in the United States showed that people frequently do not have the information they need to make the decision about family members' organ donation or do not have a clear idea about the donation process, thus increasing refusal of families towards donation consent, the main limiting factor for organ availability.(12, 13)

One clear example is the discrepancy between the willingness or goodwill to donate and the family's wishes during consent, showing that, even though studies suggest that between 69% to 75% of adults in the United States have the intention to become organ donors, half of the families do not consent to donation during interview.(14)

In order to try to solve these controversial issues and guarantee the individual's autonomy, the Center for Organ Recovery and Education CORE, operating in New York, Pennsylvania and West Virginia, adopted the policy of recording individual wishes for donation in documents, regardless of familial consent. In practice, this policy ends up informing families about the family member's wishes at the moment of interview, making families compelled to honor his/her wishes.(14)

For the CORE, respect for the autonomy of their loved one is considered to be a morally acceptable policy.

It would be appropriate to remember Berlinguer's claim that the adoption of norms and behavior that are morally acceptable and practically useful requires both the confrontation and convergence of tendencies and demands. Tolerance ceases to be sufficient when a contrast comes to life, not between the government's choice and the citizens' freedom, but rather between two or more rights, which deserve equal respect.(15)

Ethics implies individual option in the active choice. It requires the person's strict adherence to values, principles and the morals; and it is connected to the notion of individual autonomy. It aims at the human being's inner world; it asks for personal convictions that cannot be imposed by outer forces; it demands free, conscious acceptance of the norms.(16)

Professionals who work with transplantation in Brazil certainly need space to discuss their moral values and virtues in order to seek ethical competence.

The advances in new biotechnologies, as is the case of organ donation and transplantation, require reflections so that the control of their benefits can be sought by means of equal, fair distribution. Or, as argued by Garrafa, "How to control without limiting?" For the author mentioned above, the issue raised is not "I'm not going to do this, because I can't do it." anymore, but rather "I'm not going to do this, because I must not do it". Control, therefore, is neither scientific nor technical, but ethical.(17)

Apart from the prioritization in the Brazilian sanitary context, one of the commitments that must be expected from the State is an adequate legislation, followed by relevant sanitary infrastructure that promotes and facilitates the control of a whole new National Transplant System.(18)

The perspectives of treatment by means of organ transplantation will depend not only on the regulation that the governments come to establish in their countries, but also and especially on political willingness so that these systems work by enabling the conditions for this to happen.(19)

Thus, after the approval of Law no 9,434/97, one study, which assessed the knowledge doctors (993) and nurses (469) have, showed that 72.7% (218) partially knew the legislation, that is, by means of the press, and that 20.7% (62) were not aware of the Law and its alterations, and showed surprise when learning that, with the advent of this legislation, they would become organ and tissue donors. This revealed that 42.4% (101) did not agree with the legislation that had just been published.(20)

In another study, 58.4% (139) did not believe that the "single line" would be respected. The majority, 159 (66.8%), did not agree with the organ removal without the family members' consent, whereas 22.7% (54) agreed with it, and 10.5% (25) did not know. Moreover, it could be observed that 86% (204) of doctors and nurses

would donate their organs, even if the Law had not been approved, with a statistically significant difference of the 66.4% (158) who changed their opinion, after the approval of this Law. Thus, the number of donors doubled, rising from 14.3% (34) to 33.6% (80).(19, 21)

The disparity in the distribution of transplantation centers in Brazil indicates that the access for this type of treatment is not equal yet, unlike many others. In addition, it could be suggested that regional differences, such as the socio-economic-cultural profile, have impacts which have not yet been studied in the donors' and receivers' life quality results.

Bioethics, defined by Potter as "the science of human survival", with the purpose of promoting and defending human dignity and life quality, must be a helping tool to solve ethical problems for professionals who work with organ and tissue donation and transplantation.

The practice of donation/transplantation begins with themes that are always current and of vital importance for humanity: death and the extension of life.

Thus, death is seen as part of the life process and, in sickness, treatments must aim at this life's quality and the person's well-being, even when the cure is not feasible.(22)

In the last years, the predominant moral principles in Brazilian society have revealed to be of a possessive, relentlessly competitive, profit-above-all type of nature, to the detriment of being and sharing, resulting in a collective supposition which is not favorable to organ donation.(23)

The progress achieved by biology has been so extraordinary that it has caused transformations in humanity's way of living and dying itself.(24)

Besides, even though donation represents a morally good, altruistic social conduct, one may infer that it has not been incorporated into the social morals due to several reasons, such as the discredit regarding the workings and structure of the healthcare system, fund allocation, relation of trust between healthcare professionals and

patients, equal and just access, donor/receiver confidentiality, free informed consent, respect for autonomy, protection of life, and the recent, innovative character of this therapeutic possibility, still under development.

We believe this is an ethical discussion, as it deals with values, principles and norms that serve as the basis for human behavior. The basis for correct and fair conduct, supported by the responsibility for one's actions, such as not killing.

To make an ethical decision, apart from the existence of alternatives for actions, the freedom to choose and act must be given to the ethical individual, according to the decision and alternative chosen by him/her. When there is only one alternative to choose from, or when one can only act according to certain alternative, the action cannot be judged as ethical.(25)

As pointed out by Chauí, ethical deliberation is performed in the sphere of what is possible. If, at times, we cannot choose what happens to us, we can still decide what to do when facing this situation. This is why a human being's self-determination is related to his responsibility towards himself as well as the other members of society. In brief, the ethical being is independent and responsible for his actions.(26)

These actions constitute a social tool, a helpful guide to determine that which must be done in order to achieve the good life, the well-being of people living in a society regulated in a social, psychological and physical dimension.(26, 27)

Thus, we need to identify the problems that make organ donation and transplantation difficult in the first place, classifying them as being of a clinical-biological, logistic-administrative, geographical, cultural and moral nature.(28)

Consequently, problems of a clinical-biological nature refer to immunological incompatibilities and associated co-morbidities (as well as the safe diagnosis of brain death). Those of a logistic-administrative nature depend on the functioning of the institutions with proper maintenance of infrastructure and human resources for the management of the organ

donation process; those of a geographical nature are represented by the differences in technological development among the several regions of the country, which makes patients go to different places in search of better chances of treatment. On the other hand, problems of a cultural and moral nature refer to religious and moral convictions as well as the patient's and family's education.(28)

One example of such problems is the appropriation of the family member's body in the donation process, without a return date for the family in sight, as well as the difficulties to visit it in this period, thus profoundly altering the religious rituals and customs that celebrate this family member's departure.(29)

Another example concerning the donor's autonomy in life was reflected in a study performed with 69 families that donated their deceased relatives' organs, where it was observed that the decision to donate was the family's exclusively among 30 of them (43.5%). The majority of them, however, were aware of the family member's wishes (63.2% vs. 36.8%) and the fact they previously knew about his/her wishes helped them decide (90.5% vs. 9.5%).(11)

In this same study, funeral assistance, which has been provided by the city of São Paulo's City Hall since 1994, was used by the deceased donor's family members (63.2% vs. 36.8%) and these agreed with this benefit in 97% of responses. Family members that took advantage of this benefit considered it to be important (92.5% vs. 7.5%). Moreover, 51:59 (78.5%) agreed with this benefit ($p=0.002$); both, respectively, would donate again.(11)

The act of altruistic donation is based on the fact that it is sustained by kindness, detachment, unconditionality, renunciation, and even sacrifice, thus constituting an emotionally gratifying attitude by the one who performs it. Because of all this, donations represent an extraordinary social virtue.(24)

As a result, indirect benefits such as the funeral expenses or other forms to compensate the family for this act could interfere with the decision

based solely on social virtue. This question gains strength when we observed that family members expressed the wish to know if the receivers were well. It is as if they could have a compensation for the loss of a loved one through the continuity of life by someone else.

It seems that the argument of the altruistic act for organ and tissue donation is a reference point for professionals, whereas for family members there is the reality of the painful loss and continuity of life.

A recent study on altruism and organ donation incentives brings up the observation that the only one who does not benefit from the transplant is the donor's family; consequently, financial incentive would be fairer.(30)

Among those who oppose this argument, considered to be unethical, are the health professionals, who claim they do not want to be in the position of offering incentive to families, as this would harm the relationship of trust, discouraging donation. They see the direct incentive (financial) as bribery, whereas the indirect incentive (non financial, such as the funeral assistance) looks like society's reward for the donation act.(30)

In the 6th World Congress of Bioethics, one lecturer defended the idea that we need to recognize the need to compensate donors for their contribution in terms of enriching and extending human life. However, the reciprocity must be in accordance with the benefactor's particular needs. Just like the organ donor's altruism meets the patient's urgent need, the latter's reciprocity must be directed towards the donor's most urgent need. As many organ donors "suffer from poverty", they must be compensated in a manner that meets their economic needs.(31)

The results of the study previously mentioned do not confirm the hypothesis that many donors "suffer from poverty", as among those who were employed, the majority received between one to three monthly Brazilian minimum wages. Likewise, no Brazilian studies have yet defined the epidemiological profile of organ and tissue donors and receivers, so that the inequality

relation, named "north and south" by bioethicists, could be established.(15, 17, 18)

Even if we thought about the libertarian doctrine, based on the defense of rights and individual property in a pluralistic world, which justifies the purchase and sale of organs as the expression of the patient's free will, moral strangers, who do not have their basic needs met, such as education, work and income, still do not have the same conditions of free choice.

A more detailed analysis of the family members' words, as well as their agreeing with the funeral assistance, can refute the argument that deceased people's organ donation is an act of altruism, as it could be observed in the majority of publications, suggesting that the most logical approach would be to view it as an act of solidarity.

Thus, the challenge for those who work with organ and tissue procurement is to have ethical competence in order to guarantee constant improvement of this process, emphasizing adequate communication between staff and family members, besides investing in work processes that identify routine issues which make the service rendered impersonal and impolite. Finally, there is the challenge of incorporating deceased donors' family members and their experiences into the organ and tissue donation campaigns.

REFERENCES

- (1) Beecher HK, Adams RD, Banger AC. **A definition of irreversible coma.** Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. *Jama*. 1968 Aug 5;205(6):337-40.
- (2) WHO. **Draft guiding principles on human organ transplantation.** http://www.who.int/ethics/topics/transplantation_guiding_principles/en/print.html; 2004.
- (3) Alcântara L. **Doação de Órgãos.** *A Lei da vida.* Brasília. 1998.
- (4) Brasil. Ministério da Saúde, SAS. *Relatório de Gestão Secretaria de Assistência à Saúde 1998/2001.* In: SAS, editor. 2nd ed: *Ministério da Saúde*; 2002. p. 220.
- (5) Conselho Federal Medicina. **Critérios do diagnóstico de morte encefálica,** 1480. (1997).
- (6) **Lei no. 9.434** de fevereiro de 1997. *Dispõe sobre a remoção de órgãos, tecidos e partes do corpo humano para fins de transplante, e dá outras providências,* n. 9.434. Sect. 1 (1997).

- (7) **Decreto no. 2.268.** Regulamenta a **Lei no. 9.434**, de 4 de fevereiro de 1997. *Dispõe sobre a remoção de órgãos, tecidos e partes do corpo humano para fins de transplante e tratamento, e dá outras providências.* Sect. 1 (1997).
- (8) **Lei no. 10.211.** Altera os dispositivos da **Lei no. 9.434**, de 4 de fevereiro de 1997, que "dispõe sobre a remoção de órgãos, tecidos e partes do corpo humano para fins de transplante e tratamento". (2001).
- (9) Garcia VD, Abrahão MRC, Hoefelmann N. **Procura de órgãos.** In *Transplante de Órgãos e Tecidos.* Neumann J AF, Garcia, VD, editor. São Paulo: ed. Sarvier; 1997.
- (10) Manfro RC, Noronha IL, Filho APS. **Manual de Transplante Renal.** 1st, editor. São Paulo: Manole; 2004.
- (11) Roza BA. **Efeitos do processo de doação de órgãos e tecidos em familiares: Intencionalidade de uma nova doação [Doutorado].** São Paulo: Unifesp; 2005.
- (12) Siminoff LA, Arnold RM, Hewlett J. **The process of organ donation and its effect on consent.** *Clin Transplant.* 2001 Feb;15(1):39-47.
- (13) Siminoff LA, Gordon N, Hewlett J, Arnold RM. **Factors influencing families' consent for donation of solid organs for transplantation.** *Jama.* 2001 Jul 4;286(1):71-7.
- (14) May T, Aulisio MP, DeVita MA. **Patients, Families, and Organ Donation : Who Shoud Decide? The Milbank Quarterly.** 2000;78:2.
- (15) Berlinguer G. **A bioética entre a tolerância e a responsabilidade.** *Humanidades.* 1994;9(4):358-67.
- (16) Cohen C, Segre M. **Breve discurso sobre valores, moral, eticidade e ética.** *Bioética.* 1994;2(1):19-24.
- (17) Garrafa V. **Ciência, poder e ética.** In: *Seminário Internacional sobre Biodiversidade e Transgênicos.* Brasília: Anais. Senado Federal; 1999.
- (18) Garrafa V, Oselka G, Diniz D. **Saúde pública, bioética e equidade.** *Bioética.* 1997;5:27-33.
- (19) Roza BA. **Impacto da legislação dos transplantes de órgãos sobre médicos e enfermeiros de uma comunidade universitária [Mestrado].** São Paulo: Universidade Federal de São Paulo; 2000.
- (20) Roza BA, Pelizzetti N. **Postura de enfermeiros e médicos quanto a Lei dos Transplante de órgãos.** *Acta Paulista de Enfermagem.* 2000;14:2.
- (21) Roza BA, Schirmer J, Medina-Pestana JO. **Academic community response to the Brazilian legislation for organ donation.** *Transplant Proc.* 2002 Apr;34(2):447-8.
- (22) Kovacs MJ. **Bioethics concerning life and death.** *Psicol USP.* 2003;14(2):115-67.
- (23) Anjos MF. **Bioética: abrangência e dinamismo.** *O mundo da saúde.* 1997;21(1):4-12.
- (24) Garrafa V. **Bioética e Transplantes. Encontro Comemorativo dos 10 anos do "Interior transplantes";** 1997; Riberão Preto - São Paulo. 1997.
- (25) Fortes P. **O Dilema bioético de selecionar quem deve viver: um estudo de microalocação de recursos escassos em saúde [Livre Docência].** São Paulo: Universidade de São Paulo; 2000.
- (26) Chaui M. **Convite à filosofia.** 5th ed. São Paulo: Ática; 1995.
- (27) Durant G. **A bioética: natureza, princípios, objetivos.** São Paulo: Paulus; 1995.
- (28) Pessini L, Barchifontaine CP. **Problemas atuais de Bioética.** 5th ed. Loyola E, editor. São Paulo: Edições Loyola; 2000.
- (29) Sadala M. **A Experiência de doar órgãos na visão de familiares de doadores.** *J Brás Nefrol.* 2001;23(3):143-51.
- (30) Jasper JD, Nickerson CA, Ubel PA, Asch DA. **Altruism, incentives, and organ donation: attitudes of the transplant community.** *Med Care.* 2004 Apr;42(4):378-86.
- (31) Castro L. **Transplantes: Altruísmo e Reciprocidade.** *Bioética: Poder e Injustiça.* 1st ed. São Paulo: Edições Loyola; 2003. p. 427-32. □

Issues in Organ Transplantation: News from the Netherlands

By Medard Hilhorst & Leonieke Kranenburg

ELPAT

In the spring of 2007 the so-called ELPAT Platform has been initiated in Rotterdam, during a European conference on the Ethical, Legal, and Psychological Aspects of Organ Transplantation (ELPAT). This Platform will serve to establish continuity in European communication on these aspects, bring together European expertise, facilitate and structure the European research area, and help to formulate priorities in research and policy. See for further information and for the Proceedings of this conference www.elpat.eu.

Europe

Although all countries face the same problems, national regulations and geographical or local circumstances can differ substantially. Whereas, for instance, in Norway more living donations than postmortal donations take place (facilities for kidney dialysis are limited, given the low population density areas and large distances to hospitals), in Spain we see more postmortal transplantations than in other countries, due to relatively unsafe road traffic, an opt-out system and straight family request procedures. In Great Britain living kidney donations between family

members has been accepted practice for a long time, but only recently additional hindrances and safeguards have been removed for living kidney transplantations between 'emotional related' persons, such as spouses, partners and close friends. In Germany this is still an issue of debate.

Dutch Postmortal Characteristics

Different from other countries, such as Belgium, postmortal donation is regulated in the Netherlands by an opt-in system. All citizens are, regularly, asked to register their wish in a national database, with options: 1. Yes, with the choice which organs to be removed; 2. Leave the decision to the family or 3. to one specific person, and 4. No. Registration is high: more than one third of the total adult population has registered, but also the number of people who have registered as "No" is high (resp. 56.8% has opted for category 1, 12.6 for category 2 plus 3, 30.6% for category 4). Due to traffic safety, better operation techniques, hospital facilities and short distances, the availability of postmortal organs is low. Over the years we see a decrease in brain-death patients and a rise in non-heart beating procedures. Waiting lists for hearts, lungs, livers exist, for kidneys a waiting time even of 4 years (1100 persons), with a high mortality rate. The Dutch government has so far resisted the plea of many parties for system change towards an opt-out system that requires registration for all and in case of no registration presumes consent. Although the debate about the donation has an ethical core, the moral difference is not as large as it seems: both 'gift' systems are strongly based on principles of voluntariness, altruistic motives and family consent. The focus of the debate in politics turned to effectiveness. Some hold the view that explicit registration has done more harm than good: it may lead and may have led to more "No's" than without registration. Others expect not significantly more donations, only marginal effects.

Dutch living trends

The scarcity of postmortal organs has led to a fast rising number of living kidney donations, without which the postmortal waiting lists would have been much larger. At present, over 40% of

all kidney transplantations are living donor transplantations. Most of these living donors are genetically and/or emotionally related to the donor: family members, spouses and friends. It is government's policy to give equal attention to postmortal and living developments. However, some take the view that disproportional attention has been given to the postmortal track, while the living developments are largely neglected. This characterization is probably unfair. Legislation has made it possible to develop new living programmes: in addition to the regular living transplantations mentioned above, a unique nationwide living kidney exchange donation programme is in place since January 2004. In living kidney exchange donation, wherein two incompatible donor-recipient couples exchange donors, so that two new transplantations become possible, about 50% of the non-matching couples can be helped. Also unrelated, Samaritan transplantations are being performed, most of them, but not all, anonymous, and sometimes through a domino-paired procedure (wherein the Samaritan donor donates to the recipient of donor-recipient couple that had registered for exchange donation, on the condition that the exchange donor donates to the postmortal waiting list). Over the last years over 20 Samaritan transplantations have been accomplished. Ethical concerns about living donation trends mostly focus on voluntariness, in the context of personal relationships, where dependance and interdependance are at stake, and, secondly, on the risks of payment when donor and recipient know each other. Payment is illegal, but difficult to check in practice: how strict can and should we be? Thirdly, some arrangements today are 'media mediated', when people come to know each other through the media, internet, television, all kind of networks. Should we, and how can we in practice, discern between related and unrelated agreements?

Facilitate, encourage, restrict?

Although the above mentioned programmes are all feasible, the Dutch government seems to hold the (restrictive) view that these transactions all take place in a private sphere, between couples and doctors. The ethical issue is, whether or not a government should facilitate and encourage these transactions more than she presently

does, knowing that private living donations gave good effects for all: the alleviation of organ shortage, and thus lower waiting times for those on the postmortal waiting list, resulting in decreased morbidity and mortality for patients with end stage organ failure. Living donors do not only help their recipient, they also help us to solve the problem of kidney scarcity. Two ethical issues have come up pressingly: shouldn't we be more willing to respect donor's wishes and, in addition, shouldn't we be more prepared to reward donor for their willingness and their meaningful offer to donate? It leads to various and complex issues of consistency and justice. We mention a few tensions.

Tensions

In the Netherlands it is not allowed to indicate, when you are dying, before your death that you want to give a kidney to a sick relative, to some patient you know. Postmortal organs should be allocated impartially, according to the waiting list. Is this consistent with the living donation scheme, where we act according to donor's preferences? Should we change the law and give dying patients the option the donate conditionally, according to their "partial" wish? The law had the intention to rule out clear discriminatory views ("I do not want to give to black, alcoholics etc."), but partial wishes are not necessarily unfair.

Proposals in the past to give some on the waiting list, e.g. those who are registered as a donor, priority over those who are not registered were rejected, but can we really say that such a priority is unfair?

We as a society also do not grant living donors priority over others, when these donors would become in need for an organ themselves, as some countries have done. Is it unfair to reward them and offer them organ security as a compensation for what they have done to society by offering kidney?

Finally, a proposal of the Dutch Transplantation Society for a new List-paired exchange programme has also recently been rejected. This proposal suggested to give a non-matching couple in the living kidney exchange programme

the opportunity to donate to the waiting list, in exchange for a postmortal kidney. It has been turned down on grounds of justice and legal hindrances. This strict impartial position may even not permit the domino-paired arrangements on the same grounds.

It seems, in conclusion, that trends in living donation force us to reconsider the relation between the postmortal system and the expanding living programmes that have come up.

Finally

The Dutch Minister of Health has promised to present "a Master plan", to be expected in March 2008, meeting the question of ongoing organ scarcity. This Plan should also be a response to the recent advise by the Dutch Council for Public Health and Health Care, supporting payments for living kidney donors, e.g. in the form of life long health care insurance, but also payments for registration and/or postmortal donation (full text of this advise can be downloaded).

References

- M.T. Hilhorst, L.W. Kranenburg, J.J.V. Busschbach, ***Should health care professionals encourage living kidney donation***, *Medicine, Health Care and Philosophy*, 2007, 10, 81-90.
- M.T. Hilhorst, ***Directed altruistic living organ donation: partial, but not unfair***. *Ethical Theory and Moral Practice*, 2005, 8 (1/2), 197-215.
- M.T. Hilhorst, L.W. Kranenburg, W. Weimar et al., ***Altruistic living kidney donation challenges psychosocial research and policy***, *Transplantation (special features)*, 2005, 79 (11), 1470-1474.
- L.W. Kranenburg et al. ***Postmortal or living related donor: preferences of kidney patients***, *met Transplant International*, 2005, 18, 519-523.
- L.W. Kranenburg et al., ***Starting a crossover kidney transplantation program in The Netherlands: ethical and psychological considerations***, *Transplantation*, 2004, 78(2), 194-197.
- G. van Dijk, Medard Hilhorst, ***Financial Incentives for Organ Donation; an investigation of the ethical issues***, *Report and Advise of the Dutch Council for Public Health and Health Care*, October 2007 (via www.ceg.nl, choose 'english' language).□

Organ Donation And The Family Veto¹

By Martin Wilkinson

At the time of writing, the Human Tissues Bill, New Zealand's legislative rethink on the law governing dead bodies, remains stuck in Parliament. The process of replacing the ancient and pre-transplantation 1964 Human Tissues Act has been drawn out. What has held it up in particular is the controversy over the role of the family in taking organs from their dead relatives for transplantation, and specifically whether families should be able to override their relatives' desire to donate. As things stand, doctors are authorised to take organs from a person who indicated a wish to donate even if the family object but, in practice, they never do and so the family have the power to veto retrieval. This situation is not at all unique to New Zealand and nor is the controversy except, perhaps, in the extent to which it has been politically important.

While the question of the family veto raises interesting questions in philosophical ethics, it is hard to avoid the sense that much of the debate is misplaced. Those who oppose the current situation seem to have in mind something like this: a dead person adamantly wanted to donate even if against the wishes of his or her family, when in walks curmudgeonly Aunt Jane, whom the deceased has always disliked, protesting about donation and ensuring that it is blocked. What on earth has it got to do with her? And what a waste! Don't doctors know there aren't enough organs to go around?

The trouble is, the typical indication in New Zealand of a desire to donate is a tick in a box on a driving licence application, which hardly constitutes either informed consent or evidence of a desire to donate no matter how upset one's family would be as a result. (Although it might then be said that we should have a better way of informing and recording wishes.) Nor is there good reason to think that the family veto wastes organs on a large scale. Apparently, families do not usually override their relatives' wishes when they know them. And transplanters argue that the bad publicity that would inevitably follow overriding the family would cause a drop in supply. Of course, these claims require evidence, and there is some, albeit not

conclusive. They also raise this question for those who would like to override the family: how do you think it should be done? Should the police be called literally to hold the family back as their loved one's body is wheeled off? Some would no doubt call the police; still, it makes you think.

What, though, of the dead person's autonomy? Isn't that infringed upon when the family get their way, even if cases of genuine conflict between deceased and family are fewer than might be thought? Unlike several writers on transplantation ethics, I do think posthumous autonomy has moral force, and the usual counterargument that the dead cannot act autonomously because they cannot act is merely a trivial truth that misses the point entirely. But even as a supporter of autonomy rights for the dead, I do not think the family veto infringes on a right, at least when it is the medical creation it is at the moment. Dead people (or living) might have a right to offer their organs but they don't have a right to have their organs taken. What if their organs are horribly diseased? And nor do I think they have a right infringed on if the reason not take their organs is to avoid bad publicity and hence bad effects on future supply.

[1] Contributor's Note: I have covered this topic in somewhat more detail in '*Individual and family consent to organ and tissue donation: is the current position coherent?*' *Journal of Medical Ethics* October 2005 pp. 587-90; and with a lot more philosophy in '*Individual and family decisions about organ donation*' *Journal of Applied Philosophy* 24 (2007) pp. 26-40. □

Part of My Liver¹

By James Dwyer

My ex-wife called and asked if I would give her part of my liver. I asked if she could wait until I died. She said that would be too late. I was in good health, and she needed a liver transplant this year.

"Please, Frank," she said, "I'm not asking you to decide right now. Just take the blood test to see if we're compatible."

"Marie," I said, "20 years of marriage proved that we are not compatible."

"I'm not talking about that," she said. "I'm talking about our blood types. All I'm asking is for you to take a blood test and talk to the transplant team."

What could I say? I said I would, and I did. I took the test, talked to the team, and read a lot. I did my homework.

The first thing I learned is that a liver is not a kidney. You have two kidneys. You can donate one of them and live quite well with the other one. Lots of people do it. It's no big deal anymore. The doctors remove one of your kidneys, and in 2 or 3 days you're back at work. You can resume a normal life, except for kickboxing.

Livers are different. You only have one, but it can regenerate itself. If surgeons remove part of your liver, it will grow back. So that's what they do. They cut out half of your liver and implant it in the recipient.

To make things work, they need a living donor with a good liver, a recipient with a bad liver, two adjacent operating rooms, and two sets of transplant surgeons. While the surgeons in one room are cutting out half of your liver, the surgeons in the next room are cutting out the recipient's liver. Then your surgeons pass the good piece over to the other surgeons, who hook it up in the recipient. Each operation takes about 8 hr.

If things go well, you recover. Slowly. When you wake up, you have a ventilator tube in your mouth, a catheter in your bladder, a feeding tube in your stomach, some kind of drain in your abdomen, and several intravenous lines stuck here and there. If there are no complications, you need 6 days in the hospital, 3 months off work, and lots of home care.

If things don't go well, you die.

"How often does that happen?" I asked the surgeon.

"Although we have to quote a mortality rate of 1%," he told me, "we think the actual rate may be as low as 1 in 200."

"As low as?" I wanted to say. Think about it. Two hundred people are sitting in a theatre watching a

movie. One of them doesn't go home. The janitors sweep him up with the paper and popcorn.

I know all this because I did my homework. I read a lot and talked to a lot of people. But no one I talked to could tell me what I owed my ex-wife. Divorce lawyers know about legal obligations: alimony, child support, common assets, and things like that. Hospital ethicists know about moral obligations: duties to prevent harm, duties to assist, obligations based on relationships, and special obligations based on family relationships.

But who knows about my relationships? I loved my wife. That's why we got married. That's why we had a child, a lovely daughter named Sophie. Everyone said that Sophie looked just like her mother: big, intelligent eyes; long, athletic limbs; and light brown hair with four shades of red. But it was a long time before I saw the resemblance.

Kids grow up so fast. They crawl around, learn to walk, play soccer, do homework, and go off to college. The part I liked best was helping Sophie with her homework. We went through school together. We drew pictures, made up stories, wrote book reports, and solved chemistry problems. When she went away to college and got straight As, I realized that she didn't need so much help.

The kid turned out well. She has a clear head and a good heart. But it wasn't until she was in high school that I realized how much she was like Marie. One Sunday morning I was sitting in the kitchen, sipping tea and musing about life. Marie was up in bed, sleeping off the effects of the night before. I was watching the sunlight refract through the window when Sophie came down the stairs.

"Good morning, Dad," she said. "Where's Mom?"

"She's still sleeping," I said. "Would you like some breakfast? I made some oatmeal."

"Not yet," she said. "I'm going out for a run."

And then I saw that she was dressed for a run. I saw her long legs and slim butt outlined in those

stretchy tights. Standing in the kitchen, she bent over at the waist, as if she was going to touch her toes, and shook her hair down with the help of gravity. Layers of colors tumbled toward the floor and hung suspended in the sunlight. Then she funneled her hair between her hands, stood up straight, and formed a ponytail. With her long, slender fingers, she slipped the ponytail through a cloth-covered rubber band. Her fingers gave the band a half twist and slipped the ponytail through again.

"I'll be back in 30 min," she said as she headed out the door. I walked over to the window and watched as she ran up the street with long, easy strides. Her ponytail swung back and forth with the rhythm of a metronome.

Pretty hair, long legs, beautiful hands, and a good heart Sophie was just like Marie, except for the drinking. At first I thought I could change Marie's habit. Then I thought I could control the problem. Finally I just tried to shield my daughter from the worst aspects. That's how you survive a difficult marriage: Lower your expectations. But the whole thing wore me down. A month after Sophie left for college, I moved out.

One year later I filed for divorce. I'm glad Marie quit drinking, but she waited until it was too late, for her and for me. During our marriage, I was never very good at saying no, but this time I would. I was ready when she called.

"Hello," I said, sensing that this was the call I was waiting for.

"Hello, Frank," Marie said. "Do you have a minute?"

"Sure," I said, "this is a good time to talk."

"First of all, I want to thank you," she said. "My doctor told me that you spoke with the transplant team."

"Yes," I said, "I spoke to a lot of people at the hospital. Of course, the first step was the blood test."

"Frank, I appreciate what you've done already. It means a lot to me."

"I didn't do that much. I just took the test and talked to the doctors. Did your doctor tell you about the test?"

"No," she said. "Are we compatible?"

"Well, one doctor offered to lie for me and say that our blood wasn't a good match, but the truth is that you are type A and I'm type O. We are compatible. In fact, I'm compatible with everyone."

"Oh, that could be good news for me. Have you thought about my request?"

"Marie, I thought about it a lot. If you needed a kidney, I would do it. I really would."

"Frankly, I know I am asking a lot, but I'm in trouble. I'm afraid I'm going to die. A lot of people die while they're waiting for a dead donor."

"And some people die as living donors."

"Frank, I know there's a risk, but I need your help. Please just think about it some more. If you decide not to do it, I'll leave you alone. I'll try my best to find another solution. Maybe I'll ask Sophie."

I felt like I had the wind knocked out of me. I knew Sophie would say yes. That's the kind of person she is. When I got enough air into my lungs to speak, I told Marie that I needed more time to think about it, that I would call her in 2 weeks.

[1] Contributor's Note: Although the issues and problems presented in this story are real, the story itself is a fictional composite.

Reference

Transplantation Vol. 76, No. 8 pp. 1266-1267 □

Contributors' Index

Jayapal Azariah

Member, Board of Directors
International Association of Bioethics
New No. 4, 8th Lane,
Indiranagar, Chennai, India 600 020

Misao Fujita PhD MPH

Satoshi Kodama PhD

Akira Akabayashi MD, PhD

Center for Biomedical Ethics
University of Tokyo
Graduate School of Medicine
7-3-1 Hongo, Bunkyo-ku,
Tokyo 113-0033

Noritoshi Tanida

Professor and Chairman in Medical Humanities
Associate Dean of the Medical Faculty
Yamaguchi University
Graduate School of Medicine,
1-1-1 Minami-Kogushi,
Ube, 755-8505, Japan

Bartira De Aguiar Roza RN, PhD

Master Nurse
Jewish Hospital Albert Einstein
São Paulo, Brazil

Janine Schirmer PhD

Coordinator
Specialization Course on Organ and Tissue Transplantation
Nursing Department
Universidade Federal de São Paulo
São Paulo, Brazil

Medard Hilhorst

Leonieke Kranenburg

Erasmus University Medical Center
Rotterdam, The Netherlands

Martin Wilkinson

School of Population Health
University of Auckland
Private Bag 92019
Auckland, New Zealand

James Dwyer PhD

University of Pittsburgh
3708 Fifth Avenue, Suite 300,
Pittsburgh, PA 15213