# SPECIAL ARTICLE

# THE PRESENT STATUS OF KIDNEY DONATION IN THE UNITED KINGDOM

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## HISTORICAL BACKGROUND

Renal transplantation is not medically speaking a controversial subject. It is no longer an experimental procedure. The first renal transplant was done in the early 1950's, nearly 30 years ago in Massachusetts in the U.S. and since then literally hundreds of thousands of renal transplants have been carried out. There has been a considerable growth in recent years in renal transplantation in the U.K. Despite this, the demand for kidneys may give an idea of the magnitude of the problem. In 1969, 200 renal transplants were performed in the U.K., in 1970 — 274, 1971 — 350, 1973 — 465, 1977 — 706 transplants but for last 4 years the number of transplantations has plateaued out at a level of about 800 or 900 per year, about 60 to a 100 per month.

## PRESENT STATUS IN THE U.K.

These figures must be seen against two kinds of backgrounds. The background of renal diseases and the background of the number of available potential donors. The renal background is roughly as follows:-
There are currently in the U.K., some 5,000 individuals on chronic renal dialysis. Of these 5,000 individuals about half would be suitable for transplantation. That ratio roughly pertains in all countries; about half patients on chronic dialysis programme would really be suitable medically to be transplanted. In addition to this pool of patients with irreversable renal failure are added about 2,000 new patients per year.

In the U.K. there are only 900 new patients starting dialysis every year and this is really a shocking state of affairs because it implies that something of the order of 1,000 individuals a year are condemned to die because they neither start on chronic dialysis programme nor are they given transplanted kidneys. In order to treat everybody an addition to the National Health Services Budget of the order of £10 million a year would be required. This is a subject which as one can imagine has given rise to a great deal of heated controversy.

The background in relation to potential donors is roughly as follows:-
There are 6,000 fatal head injuries a year in the U.K. and of these 6,000 individuals, some 4,000 would be suitable as donors. In other words they would fulfill the nationally agreed criteria for the definition of brain death and yet despite the existence of these 4,000 potantial donors, only 450 of these donors or some 11% are in fact used as donors. Why are only 11% of potential donors in fact used as donors? There are four main problems — one relating to doctors, one relating to public, one relating to available facilities and one relating to the wording of the legislation itself. All four in fact act as deterents although to a variable degree.

## THE ATTITUDE OF DOCTORS

Let us start with self criticism of doctors themselves. Doctors do not always indentify the potential donors. In other words they do not initiate the process of kidney retrival. Doctors in specialities other than renal disease may not be aware of the magnitude of the crisis in renal medicine. They may not even be aware of the potential benefits of transplantation if they were educated 20 or 30 years ago and have not followed recent developments. There is a tremendous fragmentation of expertise in all branches of medicine and other specialities are not aware of the problem in renal medicine. But there are also other problems as well. To initiate the process of salvaging a kidney is a time consuming process. You have to phone the renal transplantation team, you have to start the process of tissue typing, you have to contact relatives and so on. Doctors may be either too lazy or too busy or using various combinations of both not to do the necessary things to start the retrival process.

## THE ATTITUDE OF THE PUBLIC

There are also limitations imposed by public attitudes. The public itself may be unaware of the potential benefits of renal transplantations or if they are aware of the potential benefits, they may be too lazy to do anything about it. Opinion polls have revealed that roughly 75% in U.S. and 60% in the U.K. favour transplantation; yet only 11% and 16% of these individuals who answered these polls in the affirmative have in fact taken up kidney cards.

## SHORTAGE OF FACILITIES

In the U.K. there are problems in relation to available facilities. There is a scarcity of intensive care units in provincial hospitals providing the appropriate facilities for identification of the modern kind of potential donor which is the brain dead individual. In Singapore such a problem would not really apply as most of the head injuries and neurosurgical problems are concentrated at the Tan Tock Seng Hospital. However, it is extremely important to have the neurosurgeons on your side.

## THE LAW REGARDING KIDNEY DONATION IN U.K.

The law regarding kidney donation in the U.K. is governed by the 1961 Human Tissue Act. The wording of this Act does make it difficult for doctors to initiate the process leading to salvaging of the kidneys as we shall see later in the article.

## POTENTIAL DONORS — LIVE VERSUS CADAVERIC

Who are the donors at the moment in the transplant programme in the U.K.? The position here has drastically changed over the last 10 years. We use very few live donors now-a-days. Majority of donors are cadveric donors, i.e. donors who have died but the nature of their death has altered dramatically over the last 10 years. Few transplantation surgeons today would ever be interested in taking a kidney from someone who had suddenly dropped dead in a general medical ward or who was brought in dead to a casualty department. In the days when this was the practice, there was an unseemingly hurry and there were problems in contacting relatives. This haste and the things that went with it in fact alienated a whole generation of doctors from transplantation in general. At present the overwhelming bulk of donors are patients who have permanently lost consciousness and who have irreversibly lost the capacity to breathe as a result of catastrophic head injuries or catastrophic brain haemorrhage and where a machine has immediately taken over the function of ventilating this particular corpse. In 1968, 25% of renal donors were on ventilators at the time their kidney were taken. In 1977, 65% of the donors were on ventilators and in 1981 figures varying between 95% to 100% of donors were in fact on ventilators when their kidneys were taken.

## WHAT IS OPTING-IN AND OPTING-OUT

These terms are increasingly being used when the legal aspects of renal transplantation are being discussed. Let us now define the terms Opting-In and Opting-Out. Opting-In means there will be a central computerised register and those who wish to donate their kidneys will fill in a form and send it off to this central register. If they had filled in such a form, the doctors would be entitled to take the kidneys. That is Opting-In to the scheme of renal transplantation. Opting-Out means that anyone who did not want his kidneys to be removed after death would need to register his wishes in some specified manner and if he had not done this, the doctor would have the right to take his kidneys in the event of sudden death in the assumption of presumed consent. That is the difference between Opting-In and Opting-Out.

## A LEGAL COMPROMISE

The law in England as most laws is a rather messy compromise between these two. There is voluntary Opting-In i.e. people can take out donor cards and leave instructions in their will that they would like their organs taken for transplant purposes. There is also presumed consent of Opting-Out but subject to very powerful vetos. The kidneys may be taken when the person in charge of the body and this has been defined recently as the hospital authorities who "having made such reasonable enquiries as far as practical" believe that neither the decreased nor the relative would have objected. The law in fact prescribes and demands that an attempt be made to ascertain the views of the relatives. So it is a definite Opting-In plus a limited form of Opting-Out subject to veto. All laws are of course compromises between conflicting demands and in this situation of renal transplantation, there are at least five conflicting demands that have to be considered. There are the views of the deceased if he had expressed them. There are views of the relatives. There are views of powerful and well organised pressure groups with views about the disposal of bodies. There are of course views of the potential recipients of the large number of patients in renal failure who are also citizens of the community. And finally there are the views of the society as a whole who has to carry the economic and emotional burden of 2,000 new patients a year contracting fatal kidney diseases. My own view and those of a number of colleagues in Britain is the law as it currently stands in the U.K. is rather too heavily biased in favour of categories 1, 2 & 3, mainly the deceased, the relatives and the pressure groups and not suffi-

ciently influenced by the demands of kidney patients, their relatives and the demands of society as a whole. Obviously some sensible balance has to be achieved but it is important to try and identify what the various pressure groups really are.

## A PUBLIC OPINION POLL

In order to study in depth the public attitude towards organ transplantation in the United Kingdom a large scale opinion poll was conducted. A number of individuals were asked firstly on their views on transplantation as such, secondly on Opting-In and Opting-Out legislation. Not only were their attitudes analysed but also their arguments used and these were categorized in terms of socio-economic groups, level of education, age, religious beliefs and so on. Some very interesting data emerged from the study. 54% of the population strongly approve of transplantation at the time of the poll. Of those not in favour, 33% are "slightly" in favour or unsure and only 13% are strongly against. Those in favour of transplantation generally tend to be amongst the more educated sections of the population and among the higher socio-economic groups. Those against transplantation, a small percentage of 13% are heavily represented among people who left school before the age of 15 or in the lower socio-economic groups. It is interesting that even amongst those who are strongly in favour of transplantation, 50% said that they would certainly forget to carry donor cards if they had them. Younger people also were likely to hold donor cards than older people, and women were more likely donors than men. The argument in favour of donations is rather surprising. One may think that the motives were basically altruistic, the desire to help others and so on but when people were put to the question and asked why they were in favour of donation, the dominant answer would be that it would be a waste not to. The other large group of people were those who were pro-donation but had done nothing about it. A number of reasons were given — have not got round to it yet; need pushing; too lazy; been too busy recently and so on. Another large group found rationalisation for not doing anything about it, I do not think my kidneys would be much good; have not been feeling very well lately; I think my next of kin would not approve of the idea; generally feeling rather squeamish about the whole subject and so on.

Opposition to donation was based on a number of rather peculiar arguments. Some arguments were: too squeamish to think about it, or do not want to be messed around or cut up or want to be buried whole. Some rather selfish reasons; they are my kidneys so why should I give them away, cannot bear the thought of my kidneys inside another person or it would upset my relatives. Only 6% in fact gave specifically religious reasons for opposing transplantation. It is interesting to note a common fear amongst those who are in favour of transplantation and amongst those who were against transplantation; in both groups a fear was voiced about the fact that the organs might be taken before one was really dead. The doctors would be wanting you to die and that you might be pressed to give your organs whilst in the process of dying and so on. It is interesting to note that those fears were more widespread and more clearly articulated amongst those who were in favour of transplantation than those who were against transplantation. Such a fear was mentioned in 13% of the people who were against transplantation, whereas it were mentioned in 20% of the people who were in favour of transplantation. A more interesting fact is that this fear was mentioned in 30% of people who eventually have taken out donor cards. In other words they are the people who have thought about it and felt that although they had these fears they were not sufficient to prevent them from taking donor cards.

Regarding Opting-In or Opting-Out, some interesting data also emerged. If people were asked the straight question "Are you in favour of Opting-In?" something like 65% of people were either very much in favour or slightly in favour. Some 18% constituted the invariable "I don't know" group; some 16% of people were against Opting-In. The reason given in favour of Opting-In was that it would be very much easier for doctors; it would lead to efficiency and speed. It is more reliable and more convenient than carrying a donor card as cards get lost and so forth. The reasons given against Opting-In was a general mistrust of computers: computers break down; computers are too impersonal; not confidential enough; people might change their minds at the last minute and forget to inform the computer. Reasons of these kind were put forward at a large scale. Among the people who were asked the question about Opting-Out there was again an interesting distribution. The majority of them, in fact 74%, were against Opting-Out with the remainder undecided.

The reasons given again may be worth considering seriously if one is going to start a widespread national debate on this issue. The argument in favour of Opting-Out is that it would generate more kidneys, save more lives but the individual would still be able to choose. It was no form of compulsion.

The arguments against Opting-Out were that it was an infringement of personal liberty, that it gave too much authority to doctors, that it infringed the rights of the next of kin, that it took advantage of laziness and forgetfulness and so on. People were then asked another question which was even more revealing and that is this:- "If your government passed the Opting-Out Legislation, would you in fact Opt-Out?" In other words how would people react if such a legislation was passed and here it is very revealing because although 75% of people said they were against Opting-Out Legislation, only 22% of the people said they would in fact Opt-Out. We must realize that these 22% of people who said that they would Opt-Out include first of all the 13% people who are against renal transplants anyway, and the increase from 13% to 22% consist of those who are so incensed by the legislation that they would Opt-Out as a protest gesture against the legislation. The overriding fact is that a large proportion of people would allow their commitment to donation in general to overrule their hesitation about the particular forms chosen and this may be a developing trend in other countries.

## CONCLUSION

By and large any legislation requires highly motivated population but even with highly motivated population it does not seem to work very well. Propaganda in various countries for Opting-In has seldom been successful. This is because the kind of person who sustains the kind of fatal head injury and who would be a potential donor is usually the young healthy adult male motorcyclist who by his very choice of mode of transport seems to think that he is immortal and is the last person to take out a donor card.

Singapore's experience is therefore similar to the expereince of most countries in that even substantial propaganda has failed to increase the number of people Opting-In. There is an argument to modify existing legislation to give more weight to kidney disease sufferers and society as a whole. How this is done is best left to individual countries.