GIVING AND RECEIVING: ORGAN TRANSPLANTATION IN SINGAPORE

LIM CHEE HAN

(B.Soc.Sci.(Hons.), NUS)

A THESIS SUBMITTED FOR THE DEGREE OF MASTER OF SOCIAL SCIENCES DEPARTMENT OF SOCIOLOGY NATIONAL UNIVERSITY OF SINGAPORE

2004

Acknowledgements

Certain mistakes should only be made just once; others should never be made. The mistakes which one should avoid making are those that can only be made, just once.

Writing a thesis is nothing like playing with a pendulum, mechanically yet meaningfully convincing oneself that gravity is indeed mass x acceleration; it reminds me more of the times I used to spend on a swing. The harder I swing, the higher I have to go, and the more exhausted I get, and the lower I have to swing. How then, does one decide to swing high or low? Deciding what one decides to write can be one of the most important decisions one has to make. The process can be as unbearable as the lightness of being and the consequences can be as heavy as staying alive.

At times I stand at a corner of the playground, hesitant. Perhaps it is time to let someone else lend a push instead.

To **Professor Volker Schmidt**, my supervisor, for his honesty and willingness to lend a hand to someone whom he has just met. Without his graciousness, this thesis and other publications would be impossible.

Those who have been very encouraging about the dimly lit academic road I had wanted to take: **Dr. Alexius Pereira**, in treating me as an equal and offering much needed up-to-date advice which the old fogeys have failed to provide. **Dr. Vedi Hadiz**, who has always been very willing and optimistic about pointing out the many absurdities of academia. **A/P Maribeth**, who even though had taught me only once, had taken the effort to pen the reference letters. And the two who have left: **Prof. Ko Yiu Chung**, and **A/P Zaheer Baber** who though are more than 20hrs away by flight, taught me about the ethos of compassion and humility without the need for reciprocity. And finally **A/P Hing Ai Yun**, who demonstrated how humanism is applied in a bureaucracy.

To the Engineers: **Huan Hong**, **Darren**, **Peh** and **Rick**. The ones who have been with me through the darker hours and the ones who I can honestly say are the few whom I trust and respect. I can never adequately show my appreciation. May they have the fortunes that have evaded me.

To the philosophers: **Justin Lee** and **Alwyn Lim**. Though my seniors, they have treated me with respect and whom I had engaged in personal and philosophical discussions that had shaped much of my personality. The times spent at Suntec will always be remembered. **Vicnesh**, a philosopher trapped within circumstances, fights back resolutely with humor and honesty; a living resource that had been gravely misallocated to economics and mathematics. **Wai**, who with much courage and honesty, had acknowledged our mortal attachments and decided to take an alternative route. May his road lead to a clearer clearing than mine. **Wong Ker**, who has shown much (and needs much more) grit in the path towards righteousness.

The fairer ones: **Ling**, whom I gravely miss, and the very special one who I sincerely wish absolute happiness and peace that I had failed to provide. I will never ever forget your

sweetness. **Jo**, her chirpiness brightened many cold hours in the office, and who has taught me about the consequences of misplaced trust and empathy. **Yvette**, who had unfortunately, made a wrong turn 5 years ago. **Grace**, happily married, and hopefully will not commit those mistakes again. **Tracy**, as always, still occupies that special position in my heart. And the many more who have brushed one too many featherly touches upon my life.

The Post-grads: **Fayong** and **Ashok**, always bickering, yet taught me about the sorely scarce resource called brotherhood. My deepest hopes that their dreams be fulfilled. **Jeff**, whom I am comforted to see to have grown wiser over the years through the courageous exercise of reason. **Alice**, the most rational woman I have met in my life. **Lloyd**, whom at times, I have forgotten that I have known him for 5 years; a friend who is always willing to be allocated with the burdens. And the other comrade-in-arms: **Soon Hock, Keng We, Jee Hun, Byung Ho**, who had showed me the necessary strength and courage needed for academia, and though tattered as we all are, still doggedly hanging on together. May no one let go.

My students: **Shuzhen**, one of the few who have impressed me with her determination. **Sharon**, **Weiyi**, **Ruqi**, **Xiaojun**, **Joni**, **Yi-yang**, **Yee-long**, and others who have left a deep impression. I wish them well.

To **My Family**. Only the tears I have shed recently expresses my love for you. You will always be the most important thing in my life. To say anything more is to undermine your importance. Speech is after all, violence.

Lastly, to **Reason**, **Compassion**, and **Courage**.

Table of Contents

Ackno	owledgements	1
Table	of Contents	iii
Summ	nary	v
Chap	oter 1 :	1
The R	Research Problem: Medicine and Morality	
1. 2. 3. 4.	The Medical Problem The Demand and Supply Problem The Moral Problem The Sociological Problem	11 14
Chap	oter 2 :	21
Litera	ture Review and Methods	
	Literature Review Methods and Methodology	
Chap	oter 3 :	34
Backg	ground of Organ Transplant Medicine in Singapore	
	Legal Aspects Institutions that deal with organ failures	
Chap	ter 4 :	42
Criter	ria and Justifications Used for Allocating Organs	
1. 2. 3.	The Criteria The Underlying Principles of Criteria and Mechanisms Problems with Criteria and Justifications	46
Chap	oter 5 :	52
The S	election of Patients for Liver Transplants	
1. 2.	Admission onto the Waiting ListSelection from the Waiting List	

3.	Conclusions	74
Chap	oter 6 :	76
The S	election of Patients for Heart Transplants	
1. 2. 3. 4.	Inconsistencies and Dilemmas: Ambiguities in Organ Allocation	77 88 98 101
Chap	ter 7 :	103
The S	election of Patients for Kidney Transplants	
1. 2. 3.	Selection from the Waiting List	106 111 125
Chap	oter 8 :	127
Concl	usions	
Endno	otes	135
Apper	ndix 1: The Questionnaire	136
Apper	ndix 2: Criteria for admission into the waiting list for liver transplants-	139
Apper	ndix 3: Public UNOS criteria for selection of heart patients	140
Apper	ndix 4: The Medical Act 1972	148
Apper	ndix 5: The Human Organ Transplant Act (amended version)	151
Apper	ndix 6: The Interpretation Bill: Criteria for determining death	157
Biblio	graphy	159

Summary

Most academic research concerning organ transplants focus on the methods of procuring organs and the definition of brain death; few have been devoted to the very allocation of human organs to selected recipients. Given that human organs are life saving medical resources, the denial of access to this resource can mean the death of the patient. It is a fact that the demand for organs outstrips the supply, how then do decision-makers decide whom to let live or die?

Decision-makers often claim that allocative decisions are made using medical criteria. However, the allocation of goods or burdens (not only in the field of organ transplantation) is not an issue that can be dealt with using technical or medical means; it is an ethical issue, or more specifically, one of distributive justice. The allocation of organs goes through the three stages of the medical triage: referral, admission, and selection. Medical criteria are mostly only applicable at the admission stage, but the fact that more patients are admitted onto the waiting list than there are organs available means that a significant amount of rationing must be done at the selection stage. Selection requires much more than the application of medical criteria. Other non-medical considerations are often involved, including economic, political and ethical ones. Often, the local transplant centres themselves make the decisions, with powers vested in the hands of a few. Therefore, the values that decision-makers hold greatly influence the outcome of those decisions.

It has been shown from previous research conducted in the West that the strictness and 'objectiveness' of criteria depends a lot on the relationship between demand and supply. Criteria tend to be more strict and absolute when demand for far outstrips supply. This reflects the many non-medical aspects of organ allocation. It has also shown that modernization resulted in the individualization of morality and liberalization of organ allocation criteria. Allocative principles had moved from utilitarian emphasis towards those concerned with justice, especially for medical fields that have been around longer than others (e.g. kidney transplantations).

The cases in Singapore generally reflect the above hypotheses. Firstly, in kidney transplantation, the oldest field in all three (kidney, liver and heart), one can see the greater emphasis on notions of justice or compassion. In addition, the programme handles larger numbers of patients, which require more objective quantifiable criteria to make the allocation process easier. Heart transplantation, which deals with the smallest pool of patients, tends to be more moralistic in its approach, and uses more qualitative approaches to patient selection. Finally, liver transplantation falls in-between the two, exhibiting both moralistic and utilitarian tendencies, and employing a mixture of quantitative and qualitative approaches. All three centres reflect, generally, the values of the state ideology, which is meritocratic and non-welfarist. Therefore, allocating organs based on the principle of desert still largely remains. It is hard to predict how organs will be allocated in the future, but through this exploratory study, and with comparisons with cases from the West, one can perhaps make some informed hypotheses.

Chapter 1:

The Research Problem: Medicine and Morality

This thesis explores some of the ethical issues involved in the allocation of life-saving human organs used for heart, liver, and kidney transplantation in Singapore. Transplantation has emerged to be the preferred form of treatment for organ failures because of the improvement in surgical techniques and post-transplant care. However, this new medical option is not always available to all who require it because of organ scarcity and the cost of the surgical procedure. Difficult decisions thus have to be made regarding who is to get the limited supply of life-saving organs and ultimately, the question of who lives and who dies. A great deal of normative work has been done about how this problem ought to be dealt with in an ethically appropriate manner, but very little is known about how it is in fact dealt with in the real world (Schmidt and Lim, 2004: 2174).

The research objective of this thesis is to offer some insights into how these decisions are made in Singapore in the fields of kidney, liver, and heart transplant. This thesis is exploratory and comparative. No such research has been undertaken in Singapore before, thus this thesis serves as a foremost exploration into how organs are allocated in the country. The knowledge offered here may allow subsequent researchers to build upon, and to pursue other issues with greater precision. This thesis also incorporates a comparison with how the issue of organ allocation is dealt with by western countries. The main research on such issues has been done in America (Elster, 1992; Kilner, 1990; Fox and Swazey, 1978) and Germany (Schmidt,

1998), but fewer literature exists that focuses on Asia. This thesis serves to supplement what is already known about this issue in the West and sheds light on whether a different political, economic, social and cultural location has any possible implications on how organs are allocated.

Although organ failures are medical problems, they require more than medical solutions. The fact that the demand for human organs outstrips the supply means that organs have to be rationed. How organs are rationed is not a medical problem, it is an ethical one that requires non-medical considerations. It has been shown that decision-makers in the West use fairly heterogeneous criteria to allocate organs, even though what they are dealing with, is allegedly a common medical issue. Kilner (1990), for example, demonstrated how scarce medical resources like organs and treatment in ICUs are allocated differently, with different groups of decision-makers preferring different models of allocation to others, and how decisions are justified with appeals to different principles as well. This plurality in the ways a similar problem is dealt with makes the issue worthy of a sociological investigation.

The thesis will proceed in the following manner. Firstly, the reader will be introduced to some basic medical knowledge regarding the functions and failings of the organs, and the different treatments available. Secondly, I shall present some data to show how serious the organ scarcity problem is, and henceforth move on to the ethical problem of rationing organs. Lastly, I shall show how to sociologically understand how the ethical problem is dealt with in real life.

The Medical Problem

Organ failures: an introduction

Kidney failure

Kidneys function as filters for waste products present in the blood. Their

main tasks are the removal of metabolic waste products and the regulation of the

body's water, electrolyte and acid/base balance (Forensius, 2002). In addition,

kidneys produce important hormones (erythropoietin and rennin). The final filtered

waste products are then passed through the ureters and stored in the bladder as urine.

The main causes of kidney disease in Singapore are diabetes and

hypertension (Forensius, 2002); these two are the main causes for kidney failure in

the U.S. as well (National Kidney Foundation, 2002b). 50% of all reported cases of

kidney failure in Singapore are caused by diabetes and 9% by hypertension (it is also

currently the number 6th killer disease in Singapore; Ministry of Health, 2002).

There are three main types of kidney failures:

Acute Renal Failure (ARF)

Chronic Renal Failure (CRF)

End Stage Renal Disease (ESRD)

ARF is characterized by a sudden drop in kidney functioning, indicated by a rapid

increase of toxicity in the blood. This condition is usually temporary but if left

untreated, it leads to ESRD. CRF is characterized by slow irreversible impairment of

3

kidney functioning. Again, if left untreated, it leads to ESRD (WebHealthCentre.com, 2002). ESRD, as the name implies, refers to the final and most serious stage in kidney failure. The difference between CRF and ESRD is that the former refers to kidneys that are operating at approximately 50% effectiveness while the latter refers to the total damage of the mechanisms.

ESRD cannot be treated by drugs alone. Patients with ESRD must be put on dialysis and await transplantation. Both ARF and CRF can be treated with drugs, with ARFs usually being treated with dialysis as well. Patients with ARF are given dialysis temporarily while their kidneys take the time to recuperate from the damage. Total recovery from ARF is possible, but not for CRF because under this condition the kidneys have been permanently damaged. CRF is either treated with drugs, dialysis and transplant, depending on how damaged the kidneys are. Some patients can still survive without dialysis or transplantation because attention is paid to diet and medication to take the workload off their kidneys (National Kidney Foundation, 2002a). However, for those with ESRD, a new kidney is the only way to take them off dialysis, which is a considerably uncomfortable procedure¹.

Liver failure

The liver performs over 100 functions vital to the human body's survival. It is somewhat similar to the kidney's functions in that it is responsible for cleansing the body of toxic substances. The liver also produces numerous chemicals and other substances needed by the body. It breaks down alcohol and it maintains hormonal balances in the body (HealthSquare, 2002).

The very complexity of the liver subjects it to many diseases. However, most of the diseases are rare, but there are a few common ones that are serious enough to threaten the functioning of the liver. They include hepatitis, liver cancer and bacterial infections (e.g. *E.coli*) while biliary atresia (dysfunctional bile ducts) and Wilson's disease (large buildup of copper in the liver) affect children's livers. In addition, liver problems are closely related to lifestyle as well, for liver failure is commonly caused by alcohol and drug abuse. Alcohol and drug abuse result in liver cirrhosis, which is the hardening of the liver due to damaged liver cells being replaced by scarred tissue. Liver cirrhosis is the most common form of liver failure in adults, and it is the 9th killer disease in Singapore (Ministry of Health, 2002a).

Liver cirrhosis, besides being treated through liver transplant surgeries, can be dealt with by eliminating the underlying cause of the disease. Besides trying to cure hepatitis or cancer (the causes of liver cirrhosis), most of the treatment is supportive in nature. In other words, the liver is given a lighter workload in order for it to recover (similar to treatments for acute renal failure). This can include abstinence from alcohol or other chemicals, and undergoing specialized diets like diuretics (fluid diet). Such form of 'supportive treatment' is also applied in the post-transplant stages, and compliance with such treatments is often seen to be essential for post-transplant prognosis. In addition, liver dialysis may become a feasible treatment alternative in the future as well, but it is currently still in the experimental stage of development.

Heart failure

Heart diseases are the 2nd most common killer ailments in Singapore, trailing closely behind cancer. They also rank 2nd on the list of the top ten conditions for hospitalization (Ministry of Health, 2002a). In the National Heart Centre and National University Hospital, more than 20% of acute cardiology admissions are for heart failures (Singapore National Heart Association, 2002). Major risk factors of heart disease include unchangeable factors like age, gender, and heredity. However, there are numerous risk factors for heart disease that can be kept under control. These include smoking, obesity, and lack of exercise, stress, and diet high in fats, salt and cholesterol.

The most serious medical problem is heart failure – when the heart loses its ability to pump blood effectively. Not only does oxygenated blood fail to reach the other parts of the body, deoxygenated blood does not return to the heart as well. Therefore, heart failure results firstly in general tiredness because of the lack of oxygen in the cells for respiration, and secondly, in the congestion of the other organs (gathering of large amounts of blood in the organs) because blood fails to return to the heart. Heart failure therefore causes a host of other organ diseases as well.

Patients with heart failure are usually given supportive treatment. Medication is mainly directed at lightening the heart's workload and alleviating symptoms like the swelling of the organs and clotting of the blood vessels. Because some heart failure patients develop irregular heartbeat, which may result in heart arrest, the artificial device (the 'pacemaker') is implanted to regulate the heart beats. However,

medication only serves to halt or delay the progression of the disease. Once heart failure is established, the heart deteriorates with time. The only solution is a heart transplant. Even though artificial hearts are technically available and undergoing experiments, they are presently used only as bridging devices to maintain the life of the patient until an organic heart becomes available for transplant (ibid).

Organ Transplantation

Organ transplantation refers to the surgical removal of the impaired organ and its replacement by a functioning one. There are three types of transplantation: Human-to-human transplantation, autologous transplantation and xenotransplantation. Human-to-human transplantation refers to replacing the organs of one person with that of another person, autologous transplantation (autografts) refers to the transplantation of certain body parts from another site in or on the body of the individual receiving it (CancerWeb, 2002) and xenotransplantation refers to a transplant across different species (TransWeb.Org, 2002). Kidneys, livers and hearts can only be replaced by external sources of organs, while xenotransplantation is still in the experimental stage, therefore I will use the word 'transplantation' to refer to human-to-human organ transplants only.

Human-to-human transplants involve either cadaveric or living-donors. Cadaveric transplantations refer to transplants with organs that come from dead people and living-donor transplantations refer to that which comes from those who are still alive. Living-donor transplants can be done between people who are not related by blood, or between living-related donors and recipients. Both cadaveric and

living-donor transplant surgeries face a similar problem, which is the rejection of the donor organ by the recipient's body. This problem is dealt with by the matching of the Human Leukocyte Antigens (HLA) between the donor and the recipient of the organs and the administering of immunosuppressive medication.

Antigens are anything that induces immune system responses in the body. Antigens can be in the forms of toxins, foreign proteins, bacteria, etc. and when the body recognizes these antigens as alien particles, the body's immune system is summoned to neutralize these antigens. The agents that function as the neutralizers are called antibodies. They are protein molecules that are produced by the leukocyte or in layman's terms, white-blood cells. The human leukocyte antigen thus refers to proteins present on the surfaces of almost all cells in the body, which when in contact with antigens which are different from themselves, induce the leukocytes to produce antibodies to fight off the sources of the foreign antigens (CancerWeb, 2002).

It is therefore an advantage that the donor's antigens resemble those of the recipient. However, it is almost impossible to get a perfect match of the antigens between the donor and the recipient (unless the donor and recipient are identical twins). Higher possibilities of matches can be found between people related by blood. This is because everyone inherits six antigens that never change throughout one's life – three from the mother and three from the father. Therefore, theoretically, the closer the donor and recipients are related by blood, the lower the probability of rejection.

Currently, the World Health Organization (iKidney.com, 2002) has identified and numbered 118 different known HLAs (there may be more that have not been discovered). However, the six antigens mentioned above are usually those that require identification and matching because they are the "strongest antigens expressed by tissues" (Kimball, 2002). Research has also shown that:

- 1. "Having no mismatches provides a clear, but modest, advantage over mismatched kidneys. (This advantage is cumulative: at 17 years, 50% of the kidneys with no mismatches are still functioning while 50% of those with one or more mismatches have been lost after 8 years.)"
- 2. "However, the incremental disadvantage of additional mismatches is small. In fact, the procedures to prevent rejection are now sufficiently good that 80% of all kidneys even those with all loci mismatched can be expected to be functioning at the end of the first year."

The above two observations were gathered from research conducted on "several thousand kidney patients" (Kimball, 2002). The table below presents the results from this research:

Table 1: HLA matches and survival rates

Number of HLA	% Kidneys surviving				
mismatches	after 5 years				
0	68				
1	61				
2	61				
3	58				
4	58				
5	57				
6	56				

(Source: Kimball, 2002)

Around the world, the matching of the six antigens is widely used as the main criterion for the selection of patients (especially that of kidney transplant patients) even though HLA matching is not an absolute medical prerequisite for successful organ transplants. All organ recipients are treated with immuno-suppressant drugs like Cyclosporin. Such drugs target the immune system's reaction towards the new organ, reducing the effects of rejection by lowering the sensitivity of the immune system. However, a disadvantage of such treatments is that the overall immune system is weakened, subjecting the patient to the dangers of infection. The advancement of immunosuppressive therapy raises the question of why HLA matching is still being used to exclude patients from getting new organs. This question will be dealt with in details later.

There are certain types of patients who have rare antigen patterns, and there are those who are much more sensitive towards foreign antigens. Patients who have received numerous blood transfusions tend to become more sensitized, increasing the likelihood of rejecting a transplanted organ. Besides the recipients, the donors attract a certain amount of attention as well, primarily in the definition of death and the ways of procuring organs. Organs have to be kept 'fresh' for a certain period of time before they are used for transplantation, and the cadaveric donor's heart has to be kept working, either naturally or artificially prior to transplantation. This makes the definition of death a sticky issue to handle. This is even more problematic in Singapore because 14 percent of the population are Muslims who define death as the death of the whole body and not just the brain stem. In many countries, for the purpose of organ transplantation, death has been defined as that of the brain stem rather than that of the heart. This means that the law covering organ transplantations must make certain provisions for Muslims, and it indeed does so in Singapore. The legal stipulations relevant to transplant medicine will be elaborated in Chapter Three.

The Demand and Supply Problem

In this section, I present the seriousness of the organ shortage problem in order to highlight just how much rationing the decision-makers have to undertake. Table 2a and Table 2b present data that demonstrates the seriousness of the organ shortage problem.

Table 2a: Demand and supply of organs over the years

Year	Waiting List				Transpl	anted		Referred Donors	Actualized Donors		Deaths	S
	K	L	Н		K	L	Н			K	L	Н
				Live	Cadaver							
1991	NA	NA	NA	12	36	2	5	63	11	NA	NA	NA
1992	NA	NA	NA	15	60	1	1	107	33	NA	NA	NA
1993	NA	NA	NA	15	32	NA	2	81	17	NA	NA	NA
1994	NA	NA	NA	12	84	0	3	112	46	NA	NA	NA
1995	NA	NA	NA	8	53	1	0	84	27	NA	NA	NA
1996	528	17	NA	18	44	9	0	74	18	5	13	NA
1997	553	15	NA	14	25	15	1	NA	NA	4	24	NA
1998	574	15	12	26	42	11	1	101	22	5	18	NA
1999	607	12	9	34	54	18	5	99	28	6	21	NA
2000	636	4	21	30	44	11	1	100	NA	7	12	NA
2001	650	25	5	46	46	10	2	138	28	5	8	1
2002	666	20	7	44	30	12	2	107	16	5	14	3

Key: K – Kidneys, L – Livers, H – Hearts, NA – Not Available

Table 2a presents data on the following:

- 1) Patients on the waiting list for transplants
- 2) Number of transplants performed
- 3) Number of deaths

Note:

 The number of patients on the waiting list for transplants is compared with the actual number of transplants performed, and also with the number of deaths from missed opportunities for receiving transplants.

Table 2b: Referred and Actualized donors

Year	Referred Donors	Actualized Donors
1991	63	11
1992	107	33
1993	81	17
1994	112	46
1995	84	27
1996	74	18
1997	NA	NA
1998	101	22
1999	99	28
2000	100	NA
2001	138	28
2002	107	16

(Sources: The Gift, 2002; Ministry of Health, 2003)

Table 2b presents the following data:

- 1) Number of referred donors
- 2) Number of actual donors

Note:

• The number of referred donors versus the number of actual donors show the percentage of potential donors (accident victims who have or have not pledged their organs) in comparison to that of suitable donors. This set of numbers reflects the result of applying criteria (medical or otherwise) to

selecting donors, and of getting approvals from relatives of the deceased for the donation of the body parts.

The slots with "NA" in the tables refer to data which could not be retrieved from the relevant institutions holding those data, or which are not recorded at all. One can see clearly from the table above that the rate of transplantation has never caught up with the rate at which patients are put onto the list. The best representation of this problem is for kidney transplantation. For example, in the year 2002, only 74 out of the 666 patients on the waiting list were transplanted. That is less than 12% of the total number of patients on the list. By looking at the differences between the number of referred donors and that of actualized donors, one can also see that less than a quarter of the donor organs were actually used for transplantation. At this rate, as lamented by a kidney transplant surgeon, 'the backlog of patients alone will take us 10 years to clear' (The Straits Times, 04/08/97). However, the above figures still under-represent the real magnitude of the problem because many medically suitable patients are never admitted to the waiting list, a problem that will be addressed in the substantive chapters.

The Moral Problem

A moral problem is one that considers the provision of welfare to a party at the expense of another. In organ transplantation, giving a patient a new heart also means denying another patient that very heart. To the decision-maker, this can be a very difficult moral dilemma to deal with.

Medical and non-medical criteria

Before I can actually start talking about moral problems, it will be necessary to distinguish them from medical ones. It is thus important at this stage to make some clarifications about the usage of various terms, primarily about the difference between medical and non-medical criteria. It is not always easy to draw the line between medical and non-medical criteria, because medical reasons are often used to justify the application of non-medical criteria, and even when medical criteria are applied, they do not always guarantee the intended results. For example, it has been shown that patients with HIV do not necessarily fare worse than "normal" patients (Gow, 2001; Halpern, 2002; Kuo, 2001; Prachalias, 2001; Stock, 2001; Neff, 2002), yet in many centres, patients with HIV are excluded from the waiting list. The same applies to alcoholics who are excluded from some centres, even though they fare as well as non-alcoholics (Cohen, 1991; Glannon, 1998; MacMaster 2000). Alcoholism is the cause of 60% of all liver cirrhosis in Germany (Schmidt, 1998: 71) but very few alcoholics are actually transplanted there and 13% of surgeons participating in a US survey support the exclusion of alcoholics from transplants (Evans and Manninen, 1987: 4). It is therefore likely that many alcoholics are rejected for other non-medical reasons. Despite the above problems with making the distinction, it is still important to lay out what is commonly accepted as medical criteria.

Medical practitioners and ethicists agree that candidates for transplants should be evaluated according to the "medical criteria" of the need for and the potential benefit from treatment (Rescher, 1969: 173-186; Childress, 1970: 339-355; Caplan, 1987: 10-19); therefore, *all* patients who need and who could benefit should receive the respective treatment. However, medical knowledge does not tell one how to choose which patients to treat and which not to if there are more medically eligible patients than resources available to treat them. Medical knowledge is above all technical knowledge, meaning that it can be used only to predict outcomes of applying particular procedures for matters of diagnosis and prognosis. For example, in organ transplantation, medical knowledge can tell the physician how long a patient with liver failure can survive on medication, and how long the patient will likely live if he were to receive a new liver. It does not tell the doctor how to select between two patients who are both suffering from liver failures and who could both benefit from treatment. Medical rationality tells the doctor to provide the best possible treatment for any patient regardless of the costs of treatments or the plight of the other patients.

Decisions like the above must therefore rely on more than medical knowledge. Between, for example, a soldier and a commoner, a utilitarian might select the former. This is because utilitarianism is concerned with the maximization of general welfare; anyone who can contribute to more happiness of more people should be prioritized. Given that the soldier is responsible for protecting the lives of many others, the importance of his well-being may surpass that of a commoner from a utilitarian viewpoint. On the other hand, a deontologist will treat both as having equal value, for humans, to the deontologist, should never be used as means to the well-being of other human beings. But utilitarianism and deontology are no medical

conceptions; they are ethical positions. If a decision-maker were to decide between the two, he would be exercising his power from an ethical standpoint rather than a medical one. Often, the decision-maker does have to exercise such powers. This is because many patients are medically indicated and hence likely to benefit from new organs. The fact that there are more patients on the waiting list for organ transplant than there are organs available shows that selection decisions are inevitable.

Generally, medical concerns can be classified into two types: firstly, patients must be at the final stages of their disease, where transplantation is the best (at times the only) treatment available. Kidney failure patients however, are indicated for a transplant the moment they are on dialysis. They need not be transplanted immediately, for they can survive almost indefinitely on dialysis, but transplantation can significantly enhance their quality of life. The second medical concern is the prognosis of the patients, which weighs the individual cost and the benefit of being transplanted. Some patients are considered medically unsuitable because they suffer from cancer, diabetes or ischemic heart diseases, which make the long-term results of surgery much worse than for a "normal" patient. However, after filtering off the unsuitable candidates, the number of patients on the waiting list still exceeds the number of organs available. Therefore, many other selection criteria are implemented to compare patients with one another in the prioritization of recipients on the waiting list. And often, non-medical considerations like 'social worth' or 'quality of life' slips in at this stage to aid in the decisions.

Various non-medical principles are utilized to assist such decisions. These non-medical values often reflect everyday moral conceptions². Decisions can also be

made on economic grounds -- whether the individual is able to pay for the healthcare resource. Other reasons could be political or religious. They vary in substance and also in their operationalization. Even though different non-medical principles are used in the decision making process, the decision is an ethical one. The distribution of scarce resources is a moral or ethical problem, more specifically, a problem of distributive justice.

Distributive Justice

Issues of distributive justice are bounded by the question 'who decides who gets what, how and why'. The reality is that some organ failure patients will not receive a transplant. The consequences are serious. Being denied a new organ can mean death for liver and heart patients or years on the dialysis machine for kidney patients. Decision makers will therefore need to make painful decisions. However, it should be noted that this thesis is not concerned with judging the appropriateness of these decisions from an ethical viewpoint. Instead, it will restrict itself to a sociological analysis of the actual practices in place and the justification given for them.

The Sociological Problem

The thesis presents an empirical study of distributive justice in practice. Organ failure is a problem happening all around the globe, and many countries are already using transplantation as a viable treatment procedure. However, the fact that even within a single locality, this problem is often dealt with very differently from one transplant center to the next (see Schmidt, 1998, for examples from Germany) suggests that non-medical factors are usually involved with various social, political and economic powers at play.

The investigation into practices of distributive justice includes the question: who decides who gets what, how and why. This thesis is concerned with laying bare the different methods, criteria, and justifications of allocating organs to specific people, where these methods, criteria and justifications are used and applied by specific decision-makers within specific localities.

This means that the thesis will deal with questions regarding:

- 1. The identities of the decision makers
- 2. The different stages for the selection of recipients
- 3. The criteria for selection
- 4. The reasons for making certain selections

The area of study will then, in a nutshell, be that of the medical triage in organ transplant medicine. The term medical triage refers to "the sorting out and classification of patients or casualties to determine priority of need and proper place

of treatment" (CancerWeb, 2002), and it is generally split into three stages: referral, admission and selection. The referral stage is beyond the scope of this thesis, for referrals are usually done by general practitioners operating as small-scale enterprises. To date, there are more than 1,900 private general practitioners in Singapore. Not much is known about referrals except that transplant surgeons have complained about widespread lack of knowledge and sympathy for the importance of referring patients for transplants among general practitioners. Therefore, my concerns lie with the admission and selection of patients for transplantations.

Chapter 2:

Literature Review and Methods

This chapter presents a review of past research done on a similar topic. The purpose is to show how my thesis attempts to fill in the gaps in the knowledge about organ allocation and what I have drawn upon from past research in the construction of my own approach. This chapter will also include the methodological approach I utilize which is informed by those used by the past researchers.

For my purpose, I draw mostly upon Schmidt (1998, 1998a, 2002) and Elster (1992) for two main arguments. Firstly, the issue of organ allocation involves both medical and non-medical principles. However, decision-makers often claim to be using medical criteria when in fact, they are not. Secondly, criteria that are used in one transplant centre differ from those used by other transplant centres. This implies that the decision-makers in a given transplant centre wields a lot of power in selecting which criteria to use and which not to. The substantive parts of the thesis will attempt to show how these two arguments apply in my documentation of the organ allocation processes. The following sections will present the literature background from which these arguments were drawn from.

Literature Review

The most relevant works on the allocation of human organs were conducted in America and Germany, respectively by Elster (1992) and Schmidt (1998). Both focused on the different criteria and principles used to allocate organs at the local

rather than global level. Elster started off investigating three arenas of distributive justice in America: health, education and work, and ended up focusing on organ allocation, college admission and job layoffs. Schmidt based his investigation in Germany on how patients were selected in different transplant centres. Little sociological research was done on issues of organ transplantation in Asia, except for the work done on Japan which was more concerned with the issue of brain death (see Lock, 2002). Besides Schmidt and Elster, Kilner (1990) and Walzer (1983) contributed to the relevant literature on ethical and procedural issues of scarce goods allocation.

Elster (1992) devoted a significant amount of attention to the allocation of kidneys. In the U.S., recipients and donors are matched through an integrated database managed by the United Network for Organ Sharing (UNOS) that coordinates organ sharing between the federal states. It uses a point system to allocate kidneys, constrained primarily by three medical criteria: blood-group typing, HLA matching, and sensitization. By having one single databank that matches donors and recipients throughout the country, it allows for higher chances of organ failure patients in getting good matches for available organs³. The point system allocates merit points to firstly, the amount of time patients clock on the waiting list, secondly, the number of HLA matches, and finally the degree of sensitization (UNOS, 1989). The allocation of merit points given to sensitization and waiting time offsets what Elster calls "bad medical luck", a trade-off between equity (sensitization and waiting time) and efficiency (HLA matching).

Elster's main contribution was more conceptual than empirical. Drawing on Walzer (1983), he argues that goods or burdens come attached with different social meanings, which elicit different principles through which they are allocated. And given that those meanings are defined socially, goods and burdens are then perceived differently in different localities, and principles used to allocate such goods and burdens vary across localities.

Elster classifies organ allocation into admission and selection stages. Admission procedures compare individuals against an absolute threshold, and offer the good only to those who exceed the threshold. Medical criteria are mostly applied at the admissions stage. Selection processes compare admitted individuals with one another, usually by producing a ranking list, and accept them by starting at the top and going down the list until the good is exhausted. The transplant centres concerned, in this thesis, apply a similar differentiation of the allocation process, placing patients on a waiting list at the admission stage, and then selecting them from the waiting list.

Schmidt's work on organ allocation in Germany puts forward the argument that decision-makers often claim to be using medical criteria when in fact, non-medical ones were used. The selection of patients is essentially a non-medical issue, according to Schmidt. The number of patients who are medically indicated for organ transplants far exceeds the supply of organs. Therefore, a prioritization of patients on the waiting list must be done, and often, non-medical criteria are evoked in deciding between patients on the waiting list. The usage of medical knowledge to justify the decisions helps in dealing with the great discrepancy between supply and

demand of organs, and it also shields the decision makers from criticism from ethicists and the public (Schmidt, 1998: 58).

Kilner's (1990) "Who Lives, Who Dies?" is an investigation into the allocation of scarce medical resources in the U.S. He showed that different decision-makers apply different principles and henceforth, different criteria in the distribution of these scarce resources. The author provides a list for the commonly used criteria, and the different types of justifications given for them. Percentages of which criteria and principles were the most popular were also provided. Kilner's work supports Elter's argument about the plurality of allocative principles within localities.

The substantive findings of the above three authors will be mentioned in the later chapters, as I make comparisons between the case in Singapore and those of the West. Besides the above three pieces, other research was conducted on the issue of organ transplantation as well, but with a wider scope than the mere allocation of the organs. Fox and Swazey conducted research on the field of transplant medicine as a whole, and published two books drawing on this research: "Courage to Fail" and "Spare Parts". Both Courage to Fail and Spare Parts are empirical investigations of the activities and other aspects of the personnel involved with transplant medicine in the United States. Therefore, neither is limited to the study of allocations. They include themes like the experiences of the physicians, the relationships between the physician and the patient, and the patient's post-transplantation experiences (Fox and Swazey, 1974). Spare Parts is a sequel to Courage to Fail, where old issues are explored against a background of new treatments and healthcare policies since the

1980s (Fox and Swazey, 1992). The guiding theoretical framework of both books comes from Marcel Mauss' "The Gift" (1967). Gifts, according to Mauss, come necessarily with obligations. Given that organs are considered gifts, they are usually donated. This has implications for the laws governing organ procurement. For example, the Human Organ Transplant Act in Singapore outlaws any form of commercialization of human organs and blood. The difference between Mauss' studies and those of Fox and Swazey lies in the role of the medical worker as a mediator between the gift giver and the recipient. The insertion of these personnel also makes gift giving an issue of distributive justice when the medical worker becomes the one who allocates those gifts.

Both Elster's and Walzer's work are methodologically relevant because they recognize the existence of plurality of goods and principles, and therefore, the need for the empirical documentation of such pluralities. This serves to remind one of the necessities of empirical investigation when one tries to deal with the real life plurality in distributive justice. Schmidt's contribution to the research methods comes from raising one's awareness that decision-makers tend to involve "medicine" in justifying local decision-making processes, which allowed the data collection process to be a lot more focused. Therefore, the questionnaire in this paper, which was formulated with the help of Schmidt, was aimed at uncovering what lies underneath medical language. Besides the input into the questionnaire, Schmidt's previous research on the topic also revealed what the popular criteria were and justifications used by decision makers in the allocation of organs. This allows one to be more prepared during the actual interviews, and to ask relevant questions should the discussion deviate from the focus of the research. Finally Kilner's work serves as

an additional (to Schmidt's) pool of information on the possible criteria that decision makers can use. This feeds into both the formulation of the questionnaire and the necessary background knowledge that one needs during the interviews. Knowing the possible justifications for and weaknesses of possible allocative criteria that can be used, is helpful especially in dealing with the decision makers who are specialists adept at using technical jargon. Without any awareness of those criteria, one could easily be drawn over to participate in the medicalization process. Besides the input into the questionnaire, Kilner's work also directs the data collection process in a more focused manner. The interviews with the decision makers were the most important part of data collection, and Kilner's work was also primarily built up from interviews. This gives further support to the feasibility of the research method in this thesis.

Methods and Methodology

This chapter on methods and methodology follows from that of literature review section because much of the methods I am using come from the experiences of prior researchers doing work on the same issue. In this section, I will talk about the two types of data to be collected, epistemological issues, and finally issues having to do with the interviewing of the informants.

Type of data:

There are two types of data that are used in this thesis, namely, the background surrounding transplant medicine, and the ways in which organs are allocated. The

background knowledge consists of the medical, supply-demand, moral and sociological problems concerning organ transplantation, and the legal and institutional aspects of organ transplantation.

The information about the medical problems comes mainly from scientific journals, publications by the restructured hospitals/specialist centres, voluntary welfare organizations (VWOs) in Singapore, and foreign medical organizations. The centres and VWOs that supplied such information are those that are concerned with organ diseases and treatments. The main institutions in Singapore include the Ministry of Health (MOH), the National Kidney Foundation (NKF), the National Heart Centre (NHC), the Singapore National Heart Association, the Singapore General Hospital (SGH) centre for renal medicine and the National University Hospital (NUH) liver transplant programme. The sources are mostly publications that are written with laymen as target readers. These sources include user-friendly websites introducing readers to problems of organ failures and transplantations.

The supply-demand problem is highlighted primarily through information supplied by the national newspaper, The Straits Times Singapore, and data released by the local institutions. Problems of shortage of particular organs are the concern of different institutions dealing with those respective organs. However, NKF's wing of the Multi-Organ Donation Development (MODD) keeps track of the general organ shortage in Singapore, including lungs and corneas as well. The Singapore Renal Registry (SRR), as the name implies, collects data related to renal diseases. The Ministry of Health releases statistics on different types of diseases, which includes

the rates of organ failures in the population. Finally, the moral and sociological problems highlighted have been widely discussed in various studies done on the same issue, but in different settings.

The materials for the legal and institutional aspects of organ transplantation were found through browsing all the local news reports related to medicine in Singapore, primarily that of The Straits Times Singapore. Other sources include statements and publications by the MOH and VWOs. No complete documentation of organ transplantation as a whole has been done as yet, and this explains why I have relied heavily on newspaper clippings in order to formulate a coherent account.

The allocation of organs involves two main stages: admission and selection. The criteria used at the admission stage are not always made public, and they are also not always strictly adhered to. Therefore, besides looking for official statements about such criteria, the interviewing of the medical personnel is necessary as well. The specific ways in which the criteria are applied can only be known through interviewing the decision makers.

The identification of the decision makers comes from knowing exactly who conducts transplants surgeries. This information is obtained through the MOH, which released a list of transplant programmes available in Singapore, where they are situated, and what kinds of transplantation surgeries they perform. The second stage is to direct enquiries towards these specific transplant programmes, and finally trying to fix appointments with the directors of these transplant programmes. The contact

with the directors further informs one of any other source of information that might be relevant to the enquiry.

Sampling, validity and reliability

This research is concerned with the admission and selection criteria, therefore the most important respondents are the decision-makers. Even though at the admissions stage, many absolute criteria are used, the choice of which allocative model to use or even which part of the allocative models to use still depends on human decisions. "Medical" models include the ones used by UNOS (United Network for Organ Sharing), or other models like MELD (Model for End Stage Liver Disease) to allocate livers. Therefore, the decision makers do not only choose between the patients by applying different criteria, but they also determine who gets onto the waiting list through their choice of allocative models.

The main difficulty in sampling was basically to identify the decision makers in the organ allocation process. This was dealt with through direct conversation with directors of transplant programmes who serve as references for any other sources of data. It was subsequently found out that they are the ones who have the holistic picture of how the whole transplant programme works, from who makes the decisions, right down to the justifications for the decisions made and even how the programme will work in the future. It was also found out later that they yield significant powers in the selection of patients as well.

This research is not meant to be representative; it is an exploratory study to get a 'feel' for the field and to make some preliminary comparison with similar cases in other countries. This is due to the difficulty in getting interviews with the relevant respondents, who are usually on tight schedules and who sometimes tend to be suspicious of the intentions of a social scientist. I had, with much difficulty but fortune, managed to fix appointments with the three important respondents after approximately six months of negotiation. As mentioned earlier, the number of transplant programmes in Singapore is small, and therefore, few decision makers are involved. There are altogether six transplant programmes in Singapore: a state-sponsored heart transplant programme, one state-sponsored and one private liver transplant programme, two state-sponsored and one private kidney transplant programme. The three primary respondents (there are others who acted more as referees to these respondents) were the respective directors of the state-sponsored heart, liver and kidney transplant programmes. Therefore, the term 'decision-makers' refers to these three main respondents from this point onwards. The research design has already been employed in other countries and other previous research (e.g. Elster, Kilner and Schmidt), and the questionnaire is designed with the guidance of Schmidt who took part in one of the interviews as well.

The interviews:

The questionnaire was used only as a rough guide during the interviews, to remind oneself to cover all the possible criteria that could possibly be considered by the decision makers. This section will discuss the procedures of formulating this questionnaire, and how it was used in the actual interviews.

I used Kilner's list of possible criteria that are used by American decision makers to draw up a list for the questionnaire. The questionnaire consisted generally of a list of questions asking about the possible criteria that decision-makers use. I selected only the criteria that are used to allocate organs. Secondly, the questionnaire was further fine-tuned by Schmidt whose experience was valuable in adding the final touch to the questionnaire. Though the questionnaire might appear rather structured and 'biased', this is due to the argument of the thesis, which draws heavily upon Schmidt and Elster. The purpose is to 'tease out' the actual non-medical reasons behind the application of medical criteria.

The questionnaire (see Appendix 1 for the complete version) consisted of two sections: those that enquire about the mechanisms at the admission stage, and those used at the selection stage. The criteria that are included in the admission section of the questionnaire include:

- 1) Age
- 2) Nationality
- 3) Social worth
- 4) Personal responsibility for illness
- 5) Alcoholism
- 6) Imminent death
- 7) Socio-psychological
- 8) Compliance
- 9) HIV

The section of the questionnaire on the selection of patients was less structured. It was not composed of a list of questions that enquired about a list of possible criteria. Rather, the questions were more concerned with, for example, how a decision is made when two or more patients were equally weighted in absolute terms (medical or otherwise). Examples of the types of questions that were asked included:

- 1) What role do you give to waiting time?
- 2) Is the quality of organs taken into account?
- 3) Do you make special provision for sensitized patients?

As can be seen from the above list of possible admission criteria, they are not necessarily exclusively medical or non-medical in nature. For example, alcoholism can be seen as a social/moral or medical criterion, depending on how one defines it. Though those are the criteria that I have categorized under the admissions section, it does not necessarily mean that the respondents consider them as absolute criteria. They can be used very differently in different programmes. If they had been used in exactly the same way, then my investigations would have been unnecessary and meaningless.

The questionnaire was not adhered to rigidly because one needs to be able to follow up on particular points brought up by the respondents during the interviews. Some of these points can be new and particular only to a certain transplant centre. It is therefore important to find out how these points relate to the research question than merely trying to find out if selection criteria are applied differently. Secondly, it is

also critical to allow the respondent to elaborate as they deem fit. Strictly following the questionnaire undermines the respondents' authority as medical experts and gatekeepers. This would not be a wise move considering the small number of respondents available. It might upset the whole project altogether.

Chapter 3

Background of Organ Transplant Medicine in

Singapore

This chapter will present some relevant background knowledge regarding organ transplantation in Singapore, primarily the laws regulating organ donation/reception and the institutions that deal with the problem of organ failures. These two aspects are important to the thesis firstly because the legal stipulations regarding organ donation have their implications on the prioritization of patients for reception of organs, and secondly, the division of labor between institutions that deal with organ failures have their consequences on who makes the decisions regarding the selection of patients and how the decisions are made.

The main source of these historical materials is The Straits Times Singapore, the main national newspaper. It would make the presentation of the data messy if references were given for every piece, therefore I would only cite the sources for the more important ones. The main source is The Straits Times, therefore I would display the day, month and year of the specific report in the form 'day/month/year'. All the other data, unless otherwise stated, come from The Straits Times as well.

Legal Aspects

The primary legal bills

This section deals with the legal stipulations governing organ transplantation.

The three main bills governing organ transplantation are:

- 1) The Medical (Therapy, Education and Research) Act (1972)
- 2) The Human Organ Transplant Act (1987)
- 3) The Interpretation (Amendment) Bill (1988)
- The Medical (Therapy, Education and Research) Act (1972) makes provision for the volunteered donation of body parts for the purpose of therapy, education and research. The donor must be of sound mind and over 18 years of age, and the donated organ/organs would take the form of gifts effective upon death. The gift can be directed towards any specified donee or recipient, or be left unspecified, with the written approval of the donor or done orally in the presence of at least two witnesses. Once the intention of the donor has been registered, relatives cannot override it (Lawnet, 2002b). See Appendix 4 for the complete stipulation.
- 2) The Human Organ Transplant Act makes provision for the implied consent to donating the kidneys by an individual who is involved in an accident and who has died in a hospital. The person affected must be a

Singapore citizen or a permanent resident, between the ages of 21 and 60 years, a non-Muslim and of sound mind. The implied consent law requires individuals to formally object to donating his/her kidneys, where the Director of Medical Services will keep a register of such individuals who have opted out. If this was not done, the individual would be taken to have consented to donate his/her kidneys.

This law does not apply to Muslims who, on the other hand, would have to opt in. The main reason why the law applies differently to Muslims is due to the Islamic definition of death. The concept of death, to the Muslims, includes the death of all parts of the body. This means that the potential donor could not be kept on artificial respiration (keeping the heart beating artificially) in order to remove the organ for donation, for this would be equal to removing the organ while the person is still alive. To take into consideration this difference between Muslims and others, the law has different provisions for Islamic practitioners.

The law also covers the prioritization of recipients of the donated organs. Anyone who has registered objection would have less priority than one who has not, and Muslims who have not opted in would have less priority than non-Muslims who have not opted out. And non-Muslims who have opted out would have the same status than Muslims who have not opted in. However, non-Muslims who have withdrawn their objections would have the same priority as those who have not objected or Muslims who have opted in. Non-pledgers are 'penalized' with demerit points of minus

60, making it extremely difficult or even impossible to get a new kidney given that they need at least 40-50 points to move to the top of the list. In addition, the law prohibits the trading, selling and advertisements relating to trading or selling of organs or blood. It also makes illegal the disclosure of the identity of the donor (Lawnet, 2002a)). See Appendix 5 for the complete stipulation.

The Interpretation Bill (see appendix 6 for the complete version) is part of the Interpretation Act, which the latter is responsible for the definition/interpretation of terms used within the law in Singapore. The Interpretation Bill deals with the definition of death, critical in transplant medicine where the body has to be kept alive for the purpose of preserving the organs to be transplanted. Therefore, the interpretation of death in instances where the dying patient is a potential organ donor, would refer to the death of the brain rather than the body.

Institutions that deal with organ failures

Throughout the past two decades, many medical facilities/institutions have been established in order to deal with diseases that affect the organs. The institutions that are dedicated to coping with organ illnesses (kidney, liver and heart) are categorized according to the function they serve: Assessment of Patients, Surgery, Dialysis, and Related Functions. They are as follows:

1) Assessments of patients:

- i) Kidney:
 - Renal Unit at Singapore General Hospital
 - Kidney Transplant Programme at National University Hospital
 - Mount Elizabeth hospital
- ii) Liver:
 - Liver Transplant Programme at the National University
 Hospital (NUH)
 - Gleneagles Hospital
- iii) Heart:
 - National Heart Centre

2) Surgery

- i) Kidney:
 - SGH
 - NUH
 - Mount Elizabeth Hospital
- ii) Liver:
 - NUH
 - Gleneagles Hospital
- iii) Heart:
 - National Heart Centre

3) Dialysis

i) Restructured hospitals:

- Singapore General Hospital
- Alexandra Hospital
- ii) Voluntary Welfare Organizations:
 - National Kidney Foundation
 - Kidney Dialysis Foundation
 - People's Dialysis Centre
- iii) Private Centres (nine in total)

4) Related Functions:

- i) Asian Transplantation Society
- ii) Liver Transplant Support Programme (NUH)
- iii) National Heart Centre
- iv) Singapore National Heart Association
- v) The Society for Transplantation (Singapore)
- vi) Singapore Renal Registry SGH
- vii) The upcoming organ transplant unit proposed by the MOH.

The Renal Unit, Kidney Transplant Programme, Liver Transplant Programme and NHC are the referral centres for the respective types of organ diseases they deal with. In addition to referring patients for transplantation, the Renal Unit and the Kidney Transplant Programme assess the patients' suitability for the different types of dialysis and drugs, and the patients' level of need for financial subsidies from the VWOs as well (Kidney Dialysis Foundation, 2002). Kidney transplant surgery is done at two public hospitals, SGH and NUH, and one other private hospital, Mount

Elizabeth Hospital. Kidney transplants include both cadaveric and living-donor transplant surgery. All three hospitals provide these two types of transplantation. The Liver transplant programme at NUH provides both assessment and transplant services for patients. The same services are provided by Gleneagles hospital as well. However, Gleneagles hospital only provides living-related donor liver transplantations while NUH provides both cadaveric and living-related. The NHC is the only centre for heart transplantation and assessment of patients. It coordinates activities including fund raising campaigns and educational programmes as well.

Renal dialysis is provided by restructured hospitals, VWOs and private dialysis centres. The NKF operates 20 dialysis centres in Singapore (National Kidney Foundation, 2002b). It is the main provider of dialysis service in Singapore and it is the world's largest not-for-profit provider of dialysis care (National Kidney Foundation, 2002d). It coordinates many other activities like fund raising, educational campaigns and job placements for rehabilitated patients.

The final list of institutions shows those that are involved in various activities related to organ transplantation. These activities include

- Fund raising
- Education
- Rehabilitation
- Research forums
- Data storage
- Support group

Coordination of Activities

Those institutions given in the list are examples of organizations that are involved in organ transplant related matters. Because many issues can indeed be related to organ transplantation, for example, matters on healthy lifestyle, diet, medical technology, etc. it would not be practical to lay out each and every organization and the activities that they are concerned with. The most important institution in the list given above is the final MOH-proposed organ transplant unit, which has yet to be established formally. According to the MOH, the unit will act as a clearinghouse for transplant operations in Singapore (The Straits Times, 18/02/01), where its area of duties includes:

- Taking over Organ Donor Registry, maintaining registers of those who have pledged or opted out of the Human Organ Transplant Act.
- Being the single body to coordinate procurement of organs
- Taking charge of public education to encourage organ donation
- Auditing transplant programme

Chapter 4

Criteria and Justifications Used for Allocating Organs

The Criteria

This chapter introduces the reader to the different criteria that decision-makers may use in the allocation of organs, how they may be used, and the justifications (or principles) behind their application. These three issues are based on previous research, which shows that decision makers often claim that they use only medical criteria for this purpose, but in practice, things are much more complex. Many a times, decisions to exclude patients are based as much on non-medical criteria than on medical ones, because of the need to control the level of demand for organs (Fox and Swazey, 1974; Aaron and Schwartz, 1984; Schmidt, 1998). This chapter helps the reader to better understand why certain criteria are preferred over others, which can be explained by the principles that are valued by the decision makers. This concrete list is drawn from the types of criteria usually used by transplant centers in Singapore:

Medical criteria:

- 1. Imminent death (or urgency)
- 2. Blood-group typing
- 3. Prognosis (both short and long-term)
- 4. HIV positive

- 5. Sensitization
- 6. HLA matching
- 7. Quality of organs

Non-medical criteria:

- 1. Nationality/residency
- 2. Personal responsibility for illness
- 3. Social worth/moral worth

Semi-medical criteria:

- 1. Age
- 2. Alcoholism
- 3. Socio-psychological well-being
- 4. Availability of social/emotional/financial support
- 5. Compliance
- 6. Retransplants
- 7. Waiting time

The list above comprises three groups of criteria. Firstly, medical criteria used to determine a patient's need for a transplant and prospects if transplanted. Secondly, non-medical criteria like moral worth and finally, criteria that fall somewhere in-between medical and non-medical criteria.

Application of criteria

Medical criteria are generally used for the sake of saving or prolonging the lives of patients with organ failures. For example, HLA matching is said to provide better long-term prognosis for the transplanted patient.

Residency or citizenship is a non-medical criterion; it has got nothing to do with the patient's prognosis. Personal responsibility for illness (or self-infliction) reflects an emphasis placed on retribution. For example, new hearts may not be given to smokers because this group of patients is treated as those who had destroyed their own hearts. If the rejection of smokers is used as a medical criterion, then smokers should be required to quit this habit rather than be rejected outright. This then becomes a question of compliance and not retribution. Social worth refers to the potential of the patient to bring welfare to other people while moral worth refers to the very moral value of the identity of the person. For example, a drug-addict with dependents can be seen as having higher social worth, but seen as having lower moral worth. Application of both criteria does not provide better post-transplant prospects at all, but are nevertheless used in some cases.

Lastly, many criteria fall somewhere in-between medical and non-medical ones because of their somewhat ambiguous nature. Age, for example, is often claimed to ensure better long-term prognoses by denying older patients access to transplants. However, they can also reflect the value placed on social worth or moral worth if younger patients are seen to have more potential to contribute to social

welfare, or that older people are simply viewed with discrimination. Alcoholism too is ambiguous in that it can either reflect an emphasis on the requirement for compliance (they need to practice abstinence) with post-transplant treatment or on retributive justice (they are rejected outright). In the U.S., government funding was easier to obtain should the patients under treatments be innocent victims of their illness (Caplan, 1987: 7). This can very well be another reason why alcoholics are rejected but medicalized as an issue of compliance. Socio-psychological criteria include examples like mental illness or low IQ. Mentally ill patients may be rejected for various reasons, for example, as is for those with low IQ, they are rejected for not being able to comply with medical treatment. They can also be rejected based on principles of social or moral worth as well. Availability of social/emotional/financial support often reflects concerns with compliance, but may also be used for the sake of ensuring a higher quality of life.

It can thus be seen that the criteria in the above paragraph can often be used to ensure compliance. Compliance is also an ambiguous criterion primarily because of the difficulty of measurements. It is difficult to predict if certain behavioral patterns of patients actually do provide better prognoses. The requirement of compliance may reflect other concerns like retributive justice, as is illustrated earlier by the example of smoking.

Retransplants are done when patients reject previously transplanted organs. These patients are usually more sensitized than normal patients and henceforth, more likely to reject newer organs. Finally, some patients who have been on the waiting list for a longer period of time are given higher priority than others. This can reflect a

medical concern in that patients' conditions may deteriorate the longer they stay on the waiting list. Waiting time can also reflect a concern with equity: those who have waited longer should get the organs first.

The underlying principles of criteria and mechanisms

There are many vague terms that are constantly used in the justification of applying particular criteria. These terms include need, success, benefit, and outcome. Take for example, the concept of need. Because of its vagueness it can be used regularly as an overarching legitimation for the usage of particular criteria/mechanisms in selecting patients. Underlying non-medical reasons can be implied within the usage of the word 'need' or 'success'. For example, a patient might need an organ more than another because he/she has a family to support (a social worth criterion), likewise, success can mean improving the quality of life of a patient or lengthening his/her life. The term's meaning is often ambiguous.

This section attempts to present the principles behind the usage of particular criteria. These principles come in many various forms, and therefore are hard to categorize systematically. However, I will attempt to classify the above list of criteria in accordance to their underlying principles.

Desert or Retribution:

The majority of non-medical criteria operate on the philosophy of desert, that medicine is applied for the sake of providing 'dues' to or withholding them from people who deserve/do not deserve medical goods. For example, a father 'deserves' an organ because he is more socially worthy (social worth) in that he is 'useful' to his wife and children. Or a homosexual does not 'deserve' a new organ because he is seen as morally contemptible (moral worth). Also, a patient might be seen as not deserving of a new organ because he/she was responsible for spoiling it in the first place (self-infliction). And finally, a citizen is prioritized over a foreigner because the citizen deserves the organ more because he contributes more for the country's well being. It is possible to argue that since the aged do not have long to live anyway, the younger patient deserves the good more than the former. The mechanism of waiting time can also be based on desert, in that the effort and time spent on the waiting list should be rewarded with a new organ.

Duty:

Some patients are selected over others because surgeons feel that they have a duty towards these particular categories of people (Beauchamp and Childress, 1979: 174). This can be illustrated by how some centres prioritize retransplant patients over others or that children are prioritized over adults. Prioritizing retransplant patients is done so because doctors feel that they have a commitment to fulfill once they start treating particular patients, and they stick with the patients while compromising success

Success:

There are two main ways in which the notion of success is used in transplant medicine (Schmidt, 1998: 56). Firstly, success refers to the cost-benefit ratio for a given patient, and secondly, to the number of years the organ or the transplanted patient survives. Socio-psychological criteria are generally used to ensure success through getting the patients to comply with medical treatments. The main problem with using this criterion is that it is difficult to measure things like compliance, emotional resilience, etc. In fact, such difficulties result in a lot of ambiguity, which allows various non-medical preferences to get involved. For example, a mentally ill patient could be rejected because of discrimination, but is justified on grounds of the requirement for compliance (Lefebvre, 1980: 182; Young, 1975: 443; Ramsey, 1970: 249).

Medical criteria, like socio-psychological criteria, are based on the idea of success as well; that medicine must grant success in its application. However, decision-makers drawing on the same notion of success can end up with very different conclusions when applying it to individual cases. This means that the selection criteria derived from the notion of success can be quite diverse. If success means both the lifespan of the organ/patient or the cost/benefit ratio, younger patients will be of higher priority than older ones. However, this is justified by the argument that older patients do not fare as well as younger, though no medical evidence can be used to support this argument (Neuberger, 1999; Lamping, 2000; Cimato 2002; Hesse et al, 1995). In fact, some physicians in Britain had admitted to deceiving the aged about the latter's poorer prognoses, just to make rationing decisions easier (Aaron and Schwartz, 1984: 35). Medical criteria can be based on need as well, in

that medical goods should go to those who are the sickest. Age, if used to indicate need, favor the old because they will probably be sicker.

Though the application of age criteria serves more of a utilitarian concern than a medical one, it is still widely applied in many western countries⁴. Other criteria like HIV infection, blood group typing, sensitization, etc. are all concerned with success rather than need, because all these criteria ensure that the patient will enjoy long-term outcome after the transplant. However, how these criteria are judged can be quite different. For example, in the UNOS system, sensitized patients are given merit points for the sake of fairness. However, doing this will compromise on success, which a Singapore transplant centre emphasizes instead.

Problems with criteria and justifications

There are three main types of problems that decision-makers face when they attempt to come up with criteria. Firstly, a definitional problem; how do they define 'dues', 'benefits' and 'need'? Secondly, how can they be certain that the application of certain means will yield desired outcomes? And finally, how do they justify using those criteria and having those outcomes?

Definitional problems are not just about placing priorities on certain goals so that one can choose between them. They also cause the problem of resolving contradictions between those goals. For example, the emphasis on obtaining success often contradicts that of fulfilling need (Schmidt, 1998: 71; Kilner, 1990: 116, 126).

If multiple goals are desired and yet they contradict one another, how does one make a choice? For example, patients who spend too much time on the dialysis machines tend to deteriorate, yet if they are transplanted early, it will not be fair to others who have waited for long. Therefore, the selection of an optimum timing is a kind of compromise between success and fairness. And different surgeons have different measurements for determining the best time for a transplant ("Patient", 1969).

A highly deserving individual might not necessarily need a new organ. Someone who has been on the waiting list for 10 years might not necessarily be as sick as another who has been waiting for just a year. An urgent case might not necessarily be a successful one. A person who needs a new organ urgently because he is very sick will have a worse prognosis than one who is less sick. Finally, an elderly patient who has contributed much to society might be seen as deserving a new organ, but the prognosis will be worse than that of a younger patient. Such complexities in transplant medicine cannot be resolved by medical means, because medicine provides no guidance in dealing with them.

General definitional problems faced by the decision makers also include, as discussed earlier, clear-cut differentiations between medical and non-medical criteria. A good example is the criterion of age. The usage of age as a medical or non-medical criterion also defines whether it is to be used as an absolute or relative contraindication. Absolute contraindications are strict thresholds that patients are compared against, and those who do not meet the standards are immediately excluded. Relative contraindications are based on variables that might add to the overall 'unfitness' of the patient for transplantation. They affect, to different degrees,

the prognosis of the patient if he were to undergo a liver transplant. These variables are called 'relative' because they can affect one another and henceforth produce additional medical problems that can, as a result, become contraindications. A second example of ambiguities between medical and non-medical criteria will be the usage of psychological criteria. Psychological 'fitness' depends a lot on social factors (e.g. emotional support from kin) while psychological illnesses are treated with medicine therefore, it is not always easy to tell if it is a medical or a social criteria (Kilner, 1990: 97-101).

Chapter 5

The Selection of Patients for Liver Transplants

This chapter discusses the allocative issues concerning liver transplantations. The nature of the problems encountered in liver transplantation fall in-between those of heart and kidney transplantations. This is primarily due to the availability of split-liver transplant procedure and liver dialysis. Split-liver transplantation makes liver transplants resemble kidney transplants in a certain sense because of the possibility of having living-donor transplantation. However, liver failures differ from kidney failures because liver dialysis is still experimental⁵; liver patients cannot be kept alive for a long time on dialysis the way that kidney patients can.

To protect the identities of the respondents, I shall name the liver transplant programme Programme L, the heart transplant programme Programme H, and the kidney transplant programme Programme K. Likewise, the liver transplant decision maker who was interviewed will be referred to as TxL, that of heart transplant TxH, and kidney transplant, TxK.

<u>Introduction to programme L:</u>

The waiting list (year 2001) at the programme is 21, with the likelihood that only about 50% of these patients will receive new livers. Till the year 2000 since the first liver transplant in 1990, the programme has done 82 transplants, but 116 deaths have occurred due to organ shortage. The liver transplant programme is small with donor organs becoming available at a slow rate. To alleviate this problem, the

programme procures organs from Malaysia. This is not a formal organ-sharing programme between countries, but between hospitals. And this is only done between Singapore and Malaysia because amongst the countries within the region, Malaysia's medical standard is considered high enough to ensure that organs are 'healthy' enough. So far, five livers have been imported from Malaysia.

The programme currently has four surgeons, and TxL claimed that the availability of any two surgeons is enough to deal with any emergencies. Besides the transplant surgeons, other medical personnel and patients together make up a tight-knitted community. A liver transplant means a life-long dedication to the medical scrutiny of the patient, therefore this community or network provides the necessary medical and social support for the patient.

I. Admission onto the waiting list

Programme L has a full list of indications and contraindications that are used to admit patients into the waiting list. This list is made publicly known (on a website), and the criteria are mostly expressed in very technical language (see Appendix 2 for the complete list). Besides the indications for liver transplants, the list consists of contraindications that are divided into absolute and relative. I present below, the simplified list of indications and contraindications for liver transplant as released publicly by the liver transplant programme.

Indications for liver transplant

- Cirrhosis
- Biliary Disease
- Primary Metabolic Disease
- Fulminant Liver Failure
- Hepatocellular Carcinoma

Absolute Contraindications

- Malignancy outside the liver
- Severe cardio-pulmonary disease or major medical illness
- Systemic Sepsis
- Medically or Psychologically unfit patient
- HIV infection

Relative Contraindications

- Age greater than 70 years
- Persistent Hepatitis B Infection (HBV DNA positive)
- Alcohol Dependence at least 6 months voluntary abstinence

As mentioned earlier, the primary medical indicator for a transplant is that patients must be at the final stage of organ disease. The programme uses an imminent death criterion, where patients are admitted onto the list if they have a 90% chance of dying within a year. This definition of imminent death is not applied universally, but death may be considered imminent when it is expected to happen within days or weeks in "competent medical judgements" (Meyers, 1977: 328; Jackson and Annas,

1986: 119; Jonsen et al, 1982: 32) or it can be measured in terms of probabilities as done at Programme H. As Elster argued, transplant centres do exercise some freedom in the criteria they implement and as Kilner pointed out, the medical criterion of success has been loosened in Britain as resources became more plentiful, so can the definition of imminent death itself (Aaron and Schwartz, 1984: 101-102). Even a commonly taken-for-granted medical criterion like imminent death can be defined differently according to the discretion of the transplant centre.

TxL claimed that the indications for liver transplant are all medical in nature, and that patients are admitted onto the waiting list only if they fulfill the criteria. Contraindications, on the other hand, are used to exclude patients from the list. However, not all criteria used by the Programme L at the admission stage are absolute. Included in the above list are relative contraindications as well. The contraindications are a mixture of medical, socio-psychological and non-medical criteria.

Different transplant programmes categorize different conditions differently into absolute or relative contraindications. Although the list of indications and contraindications provided by Programme L states clearly the way they differentiate between the two, the interviews with the decision makers reveal a significant level of flexibility in implementing them. This will be elaborated in greater detail later.

The contraindications used by the programme are more sociologically interesting because of the high level of flexibility with which they are applied. The applications of those contraindications have been topics of debate in transplant

medicine because of the various contradicting evidence that support their applications and in addition, due to the fact that different transplant programmes apply different standards. For example, some reports show that alcoholics experience lower survival probabilities (Scharschmidt, 1984) while others show that alcoholics fare as well as non-alcoholics (Cohen, 1991; Glannon, 1998; MacMaster 2000).

The Contraindications

A patient is not only assessed by transplant surgeons alone. Hepatologists, anesthesiologists, histopathologist, medical social worker, dietitians, psychiatrists and transplant coordinators are involved as well. The members of the committee define the nature of what constitutes a medically and psychologically fit patient. The fact that psychological fitness is considered an absolute contraindication highlights the importance of the role of the social worker and the psychiatrist in the decisions to admit patients onto the waiting list. The notion of fitness lends itself to various interpretations and levels of strictness. Studies in the West (Fox and Swazey, 1978; Schmidt, 1998; Aaron and Schwartz, 1984) have shown that under conditions of organ scarcity, allocations of organs are rarely based on medical considerations alone. The strictness of the allocative criteria changes in accordance to the number of organs available; criteria are largely a function of the relation between demand and supply (Schmidt and Lim, 2004).

Besides the explicit rejection of potential recipients with HIV infection, medical fitness is defined ad hoc. Medical and psychological unfitness are used as

absolute contraindications, but if the members of the committee can negotiate the notion of fitness, it is less than absolute. During the interviews, TxL argued that all patients on the list are competing on 99% medical criteria. However, things are more complicated than that. Besides the doctors looking at medical criteria, the psychiatrists and social workers evaluate socio-psychological factors of the patients. These factors are articulated as:

"Working environment, social support...if we see a guy who doesn't keep a schedule for the tests, then he cannot be taken seriously. We will talk to them, send them to the psychiatrist. We don't want them to lose the liver. It is better to measure it now than after the transplant. It's a big tedious process, takes about 1-2 months. He has to satisfy so many people"

As shown above, psychological fitness depends on social and environmental conditions as well. The main difficulty with including such variables lies in their measurements. How does one determine what degree or quality of social support is necessary for a transplant to be successful? Psychological fitness is actually used to secure compliance. Though one report claimed that it is taken less seriously in non-western cultures (Perkins, 1986), TxK claimed that compliance is taken very seriously at programme L. Research in America has also shown that 90% of premature graft losses are due to non-compliance, hence avoidable rejection of the new organ (Schweizer, Rovelli, Palmeri, Vossler, Hull & Bartus, 1990).

Besides psychological and social criteria, alcoholism is also a criterion that is used to indicate the likelihood of compliance as well. Rejection of alcoholic patients is justified on the grounds of poor long-term prognoses. However, it takes at least 10 years for a liver to be destroyed through alcoholism, but new livers do not, on average, last that long in the first place anyway (Schmidt, 1998). This indicates that alcoholics are rejected for other reasons.

TxL admitted that most of the time, the measurements used to predict compliance are not very accurate: "we are often wrong...we have lost patients because they are not compliant". German physicians faced this problem as well, and most transplant surgeons readily admit that sometimes, they thoroughly misjudge a case (Schmidt, 1998: 54). Still, such failures have not made Programme L more hesitant about applying the measurements. In fact, TxL believes that with experience and better resources, the measurements can be further fine-tuned.

Given that transplanters are well aware of the difficulties in measuring 'fitness', one can hypothesize about the forces driving their usage. Singapore's healthcare philosophy is essentially non-welfarist (Chua, 1995: 9-40; Rodan, 1996: 20-45; Clammer, 1993: 34-52) and meritocratic (Quah, 1981: 149-156; 1989: 122-160); perhaps the emphasis on compliance is an attempt to medicalize concerns about whether the patient actually 'deserves' the treatment. As argued by Perkins (Perkins, 1986), compliance or the willingness to take treatment is less important in non-western cultures. In its place, desert or retribution might take precedence. Non-welfarism as an ideology does not only underlie the healthcare system, a form of compulsory savings system exists in Singapore that ensures that citizens

contribute part of their salaries to a fund (Central Provident Fund) that is eventually used for future expenditures. Decision-makers' values are likely influenced by the system's underlying ethos, which is reflected in the non-medical criteria (desert) used in the allocation of organs in transplant programmes. As articulated by TxK, "Singapore finds it hard to forgive..." Given that Singapore, as an Asian country, tends to be more collectivist in its morality than western societies (Schmidt and Lim, 2004), utilitarianism tends to fit better in the society and an organization dealing with distributive issues existing within it.

Even if indeed, the objective of using psychological fitness is to secure compliance, it still reflects a weak form of utilitarianism, and not genuine medical concerns. Medical rationality and ethics only tell the doctor to do his/her best to provide a patient with the best possible treatment; whether the organ should survive as long as possible is not a question that can be answered medically. Utilitarianism is also reflected in the application of the age criterion. Age is defined in two ways: chronological and physiological. Chronological age automatically excludes patients who exceed the maximum limit (hence rendering it into an absolute contraindication) while physiological age excludes those who are 'medically unfit' because of their age (hence a relative contraindication). The relationship between chronological age and medical fitness is an ambiguous one. Medical research concludes that no strict causal relationship exists between chronological age and medical fitness for transplant (Neuberger, 1999; Lamping, 2000; Cimato 2002; Hesse et al, 1995). Therefore, exclusion of the elderly from transplantation must be due to other reasons. In fact, it reflects the ethical concern to maximize output attainable from given resources.

The age limit for liver transplants is set at 70 years. This number is higher than that for kidney transplants (60 years) even though liver transplants are more complex, thus requiring a 'younger body' for prognoses to be good. Although the liver transplant programme explicitly uses the age of 70 years as a relative contraindication, TxL revealed that physiological age is used in practice. As articulated by TxL, "A guy who is 58 might look better than a guy who is 50...it is not fixed". Long-term outcome is an important factor behind using age as a contraindication. A 58-year-old man who 'looks better' has a better prognosis than one who might be younger, but who may not live long after the transplantation. Just as compliance, the use of physiological age as a criterion reflects the utilitarian concern with maximizing the functioning years for the new liver. Regardless of whether the prognosis refers to the functioning years of the new liver or expected life expectancy for the transplanted patient, younger patients will always be of higher priority than the aged under this criterion.

The age criterion has been widely applied under conditions of extreme scarcity in many western countries (Kilner, 1990: 77-78). It directs many patient selection decisions in the U.S. and Britain (Hendee, 1986: 8; Meissner, 1986:6), and public support for it's the usage is strong (Evans and Manninen, 1987: 4). Kilner points out that age-related criteria are particularly prominent when resources are limited, using the example of Britain's renal dialysis services during the days before they became federally funded. Policies that filter off the aged even affect decisions at the stage of referrals (Berlyn, 1982:189). Physicians in the West, knowing that the elderly will not be able to access medical resources even if they are referred for it,

provide 'merciful lies' (Schmidt, 1998: 56) to these patients to prevent dashing their expectations. It is unknown whether physicians in Singapore do the same, but TxL pointed out that the small number of referrals makes the waiting list much shorter than it potentially could be.

Though prognoses play an important utilitarian role in the transplant programme, TxL later emphasized that it is the need of the patient and not the success of the transplantation that ultimately decides if someone will be admitted. The typical patient to be admitted is 'decompensated', one who

"Looks yellow, has a big tummy, losing weight... one could get liver disease without being decompensated...we choose from this decompensated group"

As a relative contraindication, the age criterion is used rather flexibly and can be compromised under certain circumstances. An elderly person might be presented as either a case of 'need' or 'success'. This shows an inconsistency in the principles that are emphasized and possible contradictions between the principles. In this case, the principles at clash are 'need' and 'success', where 'need' refers to imminent death and 'success' to long-term prognosis. This shows that even the twin medical goals of fulfilling need and providing benefit contradict one another at times (Schmidt, 1998; Neff, 2002).

It was revealed that a stronger version of utilitarianism, primarily social worth, was one of the principles that underlie the application of the age criterion.

TxL pointed out that because the younger individual would likely have a family to support, he would 'need' to come back to 'a more economically viable sort of situation'. The liver does not, then, benefit just the recipient, but his dependents as well. This reflects a communitarian/collectivist tradition of prioritizing the family and the community over the individual. An individual's worth is closely tied to his/her social networks and his/her responsibilities to other people. The social worth criterion used to be more popular in the West, but with ongoing modernization and individualization of morality, this criterion has been relaxed recently (Schmidt and Lim, 2004). One can perhaps, make the hypothesis that Singapore might follow the footsteps of the West, as can be seen in the case of the allocation of kidneys at programme K (see chapter 7). With rapid modernization, Singapore's morality might become more liberal and move towards a less collectivist and 'punishing' mode (Inglehart, 1995: 379-403).

As mentioned above, alcoholics are sometimes seen to be non-compliant; therefore, a six-month abstinence from alcohol is expected from those who want to be admitted into the waiting list. It was claimed by TxL that such requirements serve two main purposes:

- 1. Abstinence from alcohol might give the liver a moment for recuperation, and if the liver does recover to a certain extent, a liver transplant is not needed at all.
- 2. Abstinence from alcohol would allow the surgeon to 'do real value for the liver'.

Research has shown that statistically, the prognoses for alcoholics are as good as those for non-alcoholics (Cohen, 1991; Glannen, 1998; MacMaster 2000). Still, TxL believes otherwise. He argued that it is not alcohol per se that destroys the liver, but rather, alcoholism can cause the patient to mix up his medication with alcohol while being treated with immunosuppressive drugs. "It is the total picture that destroys the liver", he claimed. The 'real value' of the donor liver here is defined as the liver's usual lifespan (around 10 years). TxL believes that the lack of abstinence from alcohol would undermine this 'real value' that the transplant could offer by destroying it prematurely.

Though alcoholism is one of the most frequent causes of liver cirrhosis, Programme L has not seen many such cases. It was not revealed by TxL whether self-infliction could be or is being used as a contraindication to being admitted to the list or to being prioritized once on the list. But as argued earlier, the non-welfarist ideology governing the distribution of resources in Singapore suggests that self-infliction can deprioritize a potential liver recipient. Such forms of non-medical criteria are left to the panel, primarily the psychiatrist. "It is not a blanket rule...we cannot be the expert...we might seek a 2nd opinion", was what TxL said. Nonetheless, alcoholism is medicalized as an issue of compliance, which is not easily measured (Simmons and Simmons, 1979: 369; Davidson and Scribner, 1967: 8), even with the help of social workers and psychiatrists.

Medical research has shown that patients with HIV infection do not necessarily fare worse than others. In fact, cases of worse prognoses for HIV patients having undergone transplants are labeled as "statistically insignificant" (Gow, 2001).

Although the rejection of HIV infected patients from transplantation is theoretically grounded, empirical experience does not validate using it as a medical contraindication. HIV infected individuals suffer from a weakened immune system, making them more susceptible to infection, and experience more difficulties in recovering from infections. So if they were to receive a new organ, it would be introducing foreign bodies into the already weakened immune system. Together with additional immunosuppressive therapy thereafter, the prognosis of the patient is expected to be worse than that of a normal patient. All these predictions however are not verified by the actual experiences with actual transplanted HIV patients (Gow, 2001; Halpern, 2002; Kuo, 2001; Prachalias, 2001; Stock, 2001; Neff, 2002).

The justification for using HIV infection as an absolute contraindication at Programme L is that the scale of the programme is small. According to TxL, only large transplant programmes conduct transplantations for HIV infected patients. This shows that the rejection of HIV patients is not strictly medically based. Given the smaller size of the programme, it would be considered too risky to try a transplant on a HIV infected patient for it can mean 'wasting' an organ. This reflects the concern with maximizing the lifespan of the liver. So far, the programme has not seen a HIV infected patient yet.

Other admission criteria

Children and adult patients are put on different waiting lists because it is now possible to conduct split liver transplantations for children. Split liver

transplantations for children come from living related donors, where the donor is usually an adult closely related (parents or siblings) to the patient. At the moment, the pediatric list is 'nearly totally done through living related' transplantations. This reduces competition between children and adults for the same pool of livers. Perhaps, like Programme K, this is done for deontological reasons, where special groups of people (children) are given special attention. It can also be done to maximize the benefits generated by a limited pool of livers, tapping into living-related adult donors rather than relying solely on cadaveric livers.

II. Selection from the waiting list

Programme L is currently trying out the MELD (Model for End Stage Liver Disease) system implemented by UNOS in the United States in February 2002. This new system potentially replaces the old system that pays more attention to the waiting time.

"The Model for End-Stage Liver Disease (MELD) is a numerical scale, ranging from 6 (less ill) to 40 (gravely ill), that will be used for adult liver transplant." (UNOS, 2003a) ... a new system for prioritizing patients waiting for liver transplants. This system is based on statistical formulas that are very accurate for predicting which individuals are most likely to die soon from liver disease" (ibid,

2003b)...uses a mathematical formula based on serum creatinine, bilirubin, and INR. MELD scores can range from 6 to 40 (MELD scores greater than 40 are all grouped together and receive a score of 40)."

This means that the MELD system allocates livers based on the urgency of cases, using the following three criteria in ranking patients on the waiting list (ibid, 2003a):

- Bilirubin, which measures how effectively the liver excretes bile;
- INR (prothrombin time), which measures the liver's ability to make blood clotting factors
- Creatinine, which measures kidney function.

As mentioned earlier, the twin goals of need and success often contradict one another. The MELD system that measures the urgency of cases, henceforth the need for a transplant, does not ensure the patient's prognosis. This particular contradiction can be resolved by either choosing to place emphasis on need or success, or to find some middle path between the two. The application of the MELD system at Programme L is indeed some sort of a middle-path option. But instead of trying to maintain the level of success of the patient while fulfilling the need of that patient, attention is given to the overall mortality rate of all the patients on the list. What the MELD does is to give organs to those who are the sickest, and this is supposed to decrease the overall mortality rate of the group of patients on the list. Therefore, the need of a single patient is satisfied by transplanting the organ for him/her if his/her case is much more urgent, while success is achieved when a group of patients in need

are transplanted and prevented from death. Need is thus fulfilled at an individual level while success is provided at a group level.

Because the MELD system being tried out at Programme L is quite new (it was started in the year 2001), this trend (of decreasing mortality) still needs to be further verified. Therefore, MELD is still in the trial period. The previous system used by UNOS allocates organs based largely on waiting time, which resulted in higher overall mortality rate. Therefore, the switch from the old system to MELD is basically a move from the emphasis on the principles of desert/equality to that of need and success. One wonders if the shift to the emphasis on success has to do with other political or economic reasons. It is not difficult to hypothesize that the programme or the surgeons would look good if they could decrease the overall mortality rate.

Programme L is currently trying out MELD while it continues to apply its traditional criteria in selecting patients from the list. TxL is tight-lipped about how the trial is carried out. The traditional criteria are:

- 1) Medical fitness
- 2) Citizenship
- 3) Waiting time
- 4) Commitment

Medical fitness at the selection stage can be defined in an ad hoc manner. For example, a general infection would de-prioritize a patient from receiving a possible transplant. In fact, TxL said that a patient on the list who is "recovering from a

recent illness would be excluded from the list". This means that if a patient were to suffer from a bout of cold, he/she might have to be passed over even if he/she was at the top of the waiting list. This is what TxK called the physician factor, for it depends a lot on the physician on duty to determine if a patient is medically suitable for a transplant when a liver becomes available.

Although a non-citizen or non-permanent resident of Singapore is not left out of the waiting list, such individuals are given second priority. The general rule is that if an organ is not suitable for any of the Singaporeans or permanent residents on the list, the foreigner will get it. One can argue that such a general exclusion of foreigners is grounded in desert, that special privileges are accorded to Singaporeans because of their contributions to the nation. Some might also argue that it is the right of the citizen to have priority simply because he/she is a citizen of the state.

Waiting time is a mechanism and not a criterion for selecting patients because it does not take into account any substantive characteristic of the individual patient. It does not matter who the patient is; one just needs to tabulate how much time has been spent on the waiting list in order to accord priority to whoever has the longest wait. The waiting time mechanism can either be grounded in desert (that those who have been waiting the longest deserve to get the organ) or equality (where an objective indicator like time is used to prioritize patients). Waiting time is accorded less importance than medical criteria though it is used as one of the tiebreakers. TxL claims 'once you are on the list, you are competing on 99% pure medical grounds'. However, when asked to choose between one patient who has a 70% success

probability because he has long been on the list and one who has a better prognosis, TxL was quite prompt in choosing the one who has had a longer wait.

Livers *generally* become more dysfunctional as time passes, which also means that the patient becomes gradually sicker and thus needs the transplant even more. To allocate livers based on waiting time means that one is trading success for need. And as mentioned earlier in the section on MELD, this apparent dilemma is being tackled through taking a middle-path between need and success. It seems that desert is not an important factor anymore. A second problem, which is both an ethical and a technical one, that decision makers have to make, is to find out exactly what the optimal time for a transplant is. Given that livers deteriorate with time and transplanting sicker patients yields worse success rates, the surgeon would have to settle on the right time to give a patient a transplant. It is a difficult decision to make, and as articulated by TxL:

"How do you predict whether when it is the best time to have a transplant... that is almost impossible in an average situation. The scoring system is a continuous process. The criteria constantly change. It is not an easy process, because we have to... if we have 21 patients its ok but when we have 100 patients then it will be a full time job for a number of people to continuously assess the patient."

Even though the main guiding principle of the transplant programme is utilitarian in nature, there were other principles (in addition to considering the need of urgent patients) that were adhered to. The importance of commitment to the patient was revealed through the discussions about re-transplantation. Programme L has done a few re-transplants, and it was claimed that the re-transplant rate at any given transplant programme is usually between 10-15%. Organ shortage is a serious problem in Singapore, and the liver transplant programme is quite small, therefore, the re-transplants are usually done with livers from living related donors. This removes competition between re-transplant candidates and first-time recipients, much like the rationale underlying the creation of a different waiting list for children.

TxL pointed out that the medical problem associated with re-transplantation is that the patient will generally have grown sicker and more sensitized, the likelihood of rejection is higher, and the second transplanted liver will have approximately half the life span of the first. He added that a transplant patient who is a candidate for a retransplant is one who would die in one month if he/she does not get a second organ. This means that the potential re-transplant patient will score quite high on need but low on success. However, these two medical objectives are partially overridden by the commitment that TxL has towards the retransplant patient.

Priority is given to a patient who has had a transplant. TxL argued that it is because the patient is facing imminent death, and 'once we have promised the guy we make a commitment'. This is clearly a deontological position to adopt towards patients. Elster calls this attitude the 'norm of thoroughness', and he argued that doctors tend to favor patients they have treated because of biased sampling, ignoring the possibility that other patients might benefit as much or even more from similar treatments (Elster, 1992: 149). Therefore, the main ethical debate revolves around

the possibility that if doctors devote their attention to other patients rather than the retransplant candidate, those other patients could have a better chance of success (Matthieu, 1988: 44-45). However, it was noted by TxL that if the patient has a recurrent disease (e.g. cancer), then the retransplant would not be done. This is grounded on the value placed on success, because a recurrent disease will mean that the patient probably will not live long even after being given a second organ.

The question of how one compromises the demands from both the value of success and commitment to the patient is not easily answered. The process becomes more complicated as one considers the imminent death of the patient as another variable. As Schmidt has argued (1998a), medical practitioners usually have some idea of how such problems are to be resolved, independent from what ethicists or technicians suggest. Patients must be treated, and physicians do not often have the luxury of engaging in theoretical musings under the confines of scarce resources. Nevertheless, they are also aware, through their experiences, of the various contradictions between their values. Besides medicalizing distributive problems to make justifications of the decisions easier, habits and routines are formed and a reality is eventually constructed to deal with the ethical problems faced in their work. This does not, however, mean that this reality is fixed as policies or regulations; it is always negotiable but influenced heavily by both the values of the decision-makers themselves, and the overall circumstances (like the non-welfarist ideology, or the speed of modernization).

However the distributive issues are resolved, what one can see here is that the programme (or even selected decision-makers) has a great deal of discretion in

deciding what to do without interference from some objective scientific imperatives. The overarching ethical position the centre takes is still utilitarianism. In the programme, a patient with recurrent diseases will generally be given livers which are of lower quality (marginal livers).

Not only can a liver be split for split-liver living related transplantation, livers come in a variety of qualities as well. A liver is defined in the programme as being marginal when it comes from a donor who is above 40 years of age. A marginal liver will not be split, and it will be given to a patient who is relatively sicker. In other words, marginal livers are matched with marginal patients. The blood group of the liver can be considered as a component of 'grades', henceforth requiring specific placement of organs with less than optimal qualities.

Blood group matching is a medical criterion because transplanting organs from a donor with a blood group different from that of the recipient can result in serious complications and even death. Therefore, the programme groups all who are on the waiting list into their respective blood types, and they will receive only organs that come from blood groups suitable with theirs. The current waiting list (year 2003) contains about 20 patients, and after splitting them into their respective blood groups (A, B, AB, and O) each group would consist of 4-5 patients. This means that any other selection criterion that is to be applied would be used to select between 4-5 patients only, as the blood matching is an absolute medical criterion.

A special category of marginal patients exists within the pool of patients on the waiting list. These patients are considered marginal because their liver failures are

caused by cancer. Cancer is a recurrent disease, which not only destroys the liver, but can spread to other parts of the body as well. This means that getting a liver transplant will not necessarily cure the patient's illness, the cancer might recur and the patient can die of other illnesses as well.

It was explained that giving marginal livers to marginal patients is due to the small size of the liver transplant programme. It would be 'risky' (similar to not giving a HIV patient a transplant) to give an optimal liver to a marginal patient because the liver might not last as long as it should. It would then, be 'wasting' a good liver (similar to giving a liver to a non-compliant patient). This sort of attitude expresses the value placed on maximizing both the functioning years for a normal liver, and the utility of one that is marginal. Given the low procurement rate of the organs in Singapore, even marginal livers are not wasted. Transplanting marginal patients with marginal livers allows one to prolong the lives of these patients, yet it does not reduce the maximum functioning years of normal livers.

As Elster had pointed out (1992: 50), British medicine has a more utilitarian orientation than the Americans and it is because the former has a greater scarcity of resources. This results in the reduction of the scope for the norms of compassion and thoroughness. Doctors are then "forced to think in terms of incremental benefits and to spread themselves thinly over more patients" (Elster, 1992: 50). This scenario is replicated in the Singapore's case, not only for Programme L, but also for both the heart and kidney transplant programmes. As shown earlier, the rate of organ donation in Singapore is much lower than that of the West, to find utilitarianism as the main allocative principle is not surprising. In addition, Singapore's healthcare

system does not rely as heavily on third party provider like in the U.S., which means that the healthcare budget in Singapore (also keeping in mind the non-welfarist philosophy) is tighter than in the U.S. This similarity with the British National Health Service accounts for both localities' utilitarian attitude⁶.

Cancer patients are given marginal livers. Besides the quality of the liver being determined by the age of the donor, diseased livers can be considered as lower quality ones. In fact, in some transplant centres, HIV patients are transplanted with organs from HIV donors (Gow, 2001: 178). Besides matching for quality, an age-matching system used to be applied at Programme L. This system matched older livers with older patients, as articulated by TxL: "we don't like to give a 60 year old organ to a 2 year old kid". But ever since the children are placed on the living related split liver transplant list, the age matching system has not been used.

Conclusions

Programme L, not unlike other transplant programmes, follow the medical triage model of admitting referred patients into the waiting list based on a certain set of indications and contraindications, followed by selecting them from the list. It is currently trying out the MELD system where the total implementation of MELD would imply a huge shift in ethical paradigm. However, as noted by surgeon TxL, the MELD system is just a guide, and therefore not a form of mechanism that is strictly adhered to. Looking at the current selection criteria that are used, the greatest compromise will be on the usage of waiting time. Just like in the U.S., the urgency

of the case and the successes of the cases would then override the traditional allocation of dues/needs that is done through looking at the waiting time. One can see very clearly that the implementation of certain models of selection is not a medical issue, but about making choices between certain non-medical principles.

Although it was expressed that the transplant programme is '90% outcome' oriented, it can be seen that the emphases on outcome are regularly being overridden by the concern with need, understood as imminent death. In addition, utilitarian concerns are also expressed in favoring the young over the old and deontological morality bounds the surgeons to the retransplant patient. However, due to the inflated problem of liver scarcity, it can be seen that utilitarianism is still the major ethical position that is favored. Medical criteria only deal with predicting the outcome of offering health to everyone who could have it, but they do not inform one about the definition of things like need, success or benefit. Neither does it inform one which of these is more important than the others, or who should receive those medical goods. One can see the numerous inconsistencies, dilemmas and compromises that have to be made in both the implementation of certain selection models, or the favoring of certain patients over others. Medicine cannot do much in tackling these inconsistencies, dilemmas and compromises at all. Issues like need, success, or desert have nothing to do with medical knowledge.

Chapter 6

The Selection of Patients for Heart Transplants

Heart transplants are different from that of kidneys primarily because any patient with heart failure who does not get a heart transplant will die soon. This is because, there has yet to be a good enough artificial replacement for the heart. Also, split-heart transplantation is not a possibility unlike that for livers. In addition, hearts are extremely scarce in Singapore. Every year, on average, the National Heart Centre (NHC) receives about 25-30 referrals. Out of these referrals, only 8-10 are medically suitable, and out of these suitable ones, only 1-2 gets used for transplants because most of the relatives do not consent to the donation. Some of the potential donors include foreign laborers who were killed in industrial accidents, and convicts on death row.

Just like livers, hearts are heterogeneous goods as well, meaning that they come in different qualities. According to TxH, a heart transplant surgeon, 'good' hearts are those that come from men younger than 40 years old and women younger than 45. He argued that, due to the unhealthy lifestyle of Singaporeans, older donors tend to already have some degree of heart defects, with men more susceptible than women. The 'ideal' hearts come from patients who are less than 30 years old and who have died in accidents. But according to TxH, 'don't dream about them', for they are that rare. Most donors are more than 55 years old, with a history of heart problems, who are on constant medication, with high-blood pressure and who smoke and drink.

I. Admission onto the waiting list

The NHC has a full list of indications and contraindications that are used to admit patients onto the waiting list. This list is clearly formalized, but not widely distributed to the public. The NHC's list of contraindications is not separated into absolute and relative categories. Instead, it lists out on the document the finer details of the admission and selection process. The admission indications and contraindications are as follows:

Indications:

- 1. Age 13 to 60 years or older depending on the general condition of the patient.
- 2. Irreversible end-stage cardiac disease with global left ventricular dysfunction
- 3. New York Heart Association FC III with low likelihood of survival for more than one year
- 4. Left ventricular ejection fraction (LVEF) should be less than 25%
- 5. Normal function or reversible dysfunction of Liver and Kidney
- 6. Good psychological background

Contraindications:

- 1. Active infection (e.g. HIV, Hepatitis, PTB)
- 2. Recent Pulmonary Infarction

3. Insulin dependent diabetes mellitus

4. Pulmonary vascular resistance over eight unit

5. Chronic gastrointestinal diseases, e.g. peptic ulcer and colitis

6. Cancer

7. Chronic bronchitis, emphysema

8. Alcoholism

9. Irreversible dysfunction of liver and kidney

heart patients are framed in very specialized medical terms as well. Comparing the criteria used at NHC and that at Programme L, one can see that contraindications like age and psychological fitness used at the latter are classified as indications within the NHC. Regardless of how these two criteria are classified, their applications raise

Just like the criteria used for the selection of liver transplant patients, those used for

similar sociological issues. Although the NHC does not explicitly and formally

differentiate between absolute and relative contraindications, such differences were

revealed during the interviews with TxH.

The Indications

The NHC selection criteria document explicitly states that a

78

"Selection committee is responsible for identifying who should be put on the register of potential recipients, and for selecting the most appropriate recipient, on the list when a donor heart is available".

The selection committee consists of not only the surgeons, but also 'other personnel involved in the heart transplant programme'. These personnel include both psychiatrists and medical social workers. The psychiatrist will

"Examine the patient to exclude any psychological or psychiatric problems that may have adverse effects on post-transplant recovery".

The above statement shows that the psychiatrist's main role is to ensure the recipients' compliance with the post-transplant treatment. Compliance is described as fundamental to Anglo-American law (Kilner, 1990: 163), and there are indications that its usage will increase in the West in the future (Robertson, 1987: 81; Task Force, 1986: 90). As mentioned in the previous chapter, compliance plays a less important role in non-western societies. Indeed, the interviews revealed that in many selection cases, it is usually more than an issue of compliance, but a general problem of 'personality trait'. This concept of personality trait includes other issues like personal responsibility for one's own illness, social-emotional independence, etc. I will devote one section to 'personality trait' later on.

During the early days of heart transplant operations in Singapore, the age limit was between 18 and 55 years old, but it has been altered to 13 and 60 since 1997. Even though the limit was set at 55, the first heart transplant patient in

Singapore was chronologically, 59 years old (The Straits Times, 10/07/90). Age is defined physiologically and not chronologically. In fact, it was eventually revealed that age is not, in practice, an absolute contraindication, but a relative one. Besides taking into consideration the difference between the two, TxH also revealed that such age limits apply differently to Caucasians and Asians as well.

"Asians look older than our age", and "if you are 60 or 62 years old but look like you're 55, we will still consider you".

It is hard to establish the medical nature of the external appearances of individuals. However, it is still claimed that there are some 'medical concerns', primarily with that of the long-term outcome of the operation. Many centres in the West used to apply the cut-off age of 50 or 55 (Debakey and Debakey, 1983: 9, Thompson, 1983: 66), with 50 as a relative contraindication, and 55 as an absolute (Devries et al, 1984: 278; Friedrich, 1984: 73). The first two artificial heart recipients Clark and Schroeder received the implantation precisely because they could not meet the age criterion. Perhaps one can even argue that the NHC is already being more accommodating in increasing the age limit.

It was revealed later, however, that there is a 'non-medical' usage of age within the selection stage. This has got a lot to do with the issue of 'quality of life'. I will devote a section to the issue of quality/meaning of life later on.

The Contraindications

Like liver transplants, the presence of HIV (including other infections as well) is used as an absolute contraindication for heart transplants. TxH emphasized that in all organ transplantations, two medical problems are pertinent: infection and rejection. Active infection is used as a contraindication because of the high possibility of the reactivation of the infection, given that immunosuppressive therapy has to be administered after the operation. This makes other infections like Tuberculosis and Hepatitis B absolute contraindications as well. All these, as mentioned earlier, though theoretically plausible are not exactly empirically verified but NHC still uses them primarily for the sake of establishing better long-term outcome. In view of the expected worse long-term outcome projected for a patient with active infection than a normal patient, the latter would be preferred over the former. This makes the NHC appear very much utilitarian.

Alcoholism as a contraindication tends more towards being an absolute rather than a relative one. This is because the programme is very strict in excluding alcoholics from the waiting list. Alcoholism is taken to be an indicator of many other criteria as well, primarily that of "personality trait". When asked if a patient would be considered if he/she pledges abstinence from alcohol both before and after transplant, TxH revealed that this would be "an arbitrary demand" on the patient, but the psychological and the social workers' assessment will be of greater priority than this arbitrary demand. Ultimately, an alcoholic, or "drug addict who is also an ex-convict" would be excluded because of the problem of personality trait. Besides the above list of indications and contraindications, patients who are

non-Singaporeans would be of secondary priority than Singapore citizens. Foreigners will only be considered if there is no Singaporean on the waiting list.

Personality Trait

The indications of psychological fitness and alcoholism point to the emphasis on personality trait. It is used primarily as an admission criterion at NHC. TxH revealed that sometimes, they could be wrong about a patient's personality, especially in cases of alcoholism (just as what TxL said about the programme's analysis of a patient's degree of compliance). This is not surprising given that surgeons interviewed by Schmidt (1998: 54) lamented about the difficulty of measuring and predicting compliance as well. In fact, TxK pointed out that a patient might exhibit better compliance after getting a new kidney even though he/she had not been compliant while on dialysis. How then does one predict a patient's willingness to accept treatment, and how does one justify using compliance (psychological fitness as NHC) as an absolute indication? These are not easy questions to answer.

TxH had admitted that there were times when the transplanters were

"Caught by those alcoholics who say they have not been drinking...sometimes they are so sick they will say anything they want to say".

This means that at times, even after the patient has been admitted onto the waiting list, they might be assessed to be unsuitable for receiving the new heart. Personality trait then also becomes a selection instead of merely an admission criterion. This means, just as it is practiced at Programme L, the assessment of the patient continues even after he/she has 'cleared' the admission stage. It is hard to see how the personality trait of an individual (as shown later), medicalized as psychological fitness at the admission stage, is related to medicine. However, the difference between NHC and Programme L is that TxH does not make as many claims as TxL about the implementation of medical criteria only. Given that personality trait embodies many different 'subjective' qualities a patient 'should' have, it reveals how much power a single centre (or even a decision-maker) have over how it distributes its goods. So far, from the investigations conducted for livers and heart transplants, one can conclude that just like in Germany and America in the 'fortunes' of patients.

"Personality trait" embodies different sub-criteria. The primary ones are that of compliance, personal responsibility, and emotional independence.

1) Compliance is given great emphasis because, according to TxH, the post-transplant part of one's life would mean a "*lifestyle change*". The programme pays a lot of attention to post-transplant care. It has a patient support group that offers not only advice to the patients, but serves as a feedback system for the medical workers to know about the patient's lifestyle as well. One can perhaps call this a sort

of surveillance body. Alcoholism, drug abuse, smoking and criminal records are all possible indicators of personality traits. TxH pointed out that

"A lot of alcoholics are non-trustable...not compliant with medication...the fact that you succumb to all the, you know, drug abuse...it's a personality trait".

It was not revealed if the psychologists or TxH undertook such assessments, but what is important is that these are not purely medical considerations. It also reminds one of the possibility that this category of people (ex-convicts and drug addicts) are assessed on the basis of moral or social worth. The social worth criterion is used widely in the world. An international study involving 30 countries has concluded that social worth plays a significant role in the selection process (Evans et al, 1984: 6), primarily in western countries (Carter-Jones, 1983; Parsons and Lock, 1980: 74). It would thus be no surprise that it is applied at NHC as well.

Smokers are also given lower priorities partially because of the lack of compliance as well. In fact, if the smoker does not stop smoking for at least 6 months (pre-transplantation), they will not be considered at all. All these are articulated in the belief that smoking, alcoholism, drug abuse are all causes of heart problems (and other related medical problems) and that they interfere with recovery after transplants. However, it was revealed later that smokers are also denied treatment because of reasons of self-infliction.

2) Secondly, personality trait includes personal responsibility for one's own illness (self-infliction) as well. The major problem with this selection criterion is that everyone is responsible for his/her own illness in some way or another, therefore, it is difficult to justify penalizing some and not others. In fact, besides smoking, alcoholism and drug abuse, 'unhealthy lifestyle' including the 'lack of exercise' were pointed out to be the cause of chronic heart diseases. How then does one decide to pay attention to some causes and not others?

It took some probing for TxH to explicitly break down the criteria of personality trait into compliance and personal responsibility. He pointed out that 'it's all related...to me it's all a personality trait...I think both are important'. It was only through narrating the story about a particular patient that the difference between the two was revealed:

"We had one patient whom we transplanted. She had bone cancer so she went through chemotherapy and eventually that damaged her heart muscle. It's not due to her own fault. Whereas for alcohol its not, it's self inflict. So we have to differentiate between these things. If you have certain unhealthy habit resulting in you having liver cirrhosis, then...especially in an era whereby we are very short of donor organs, one has to use the donor organs more cautiously. To give them the benefit, the best benefit so to speak. This is how I look at it; unfortunately we have to be realistic in life. We would like to help everybody but sometimes you see this is what we have, we have to work within our limit."

The above extract clearly reflects TxH's ethical position about alcoholics. They are not rejected merely on the grounds of the requirement for compliance; it is also based on the principle of retributive justice, an ethical rather than a medical requirement.

3) Thirdly, emotional independence was the third most important factor within the criterion of personality trait. It is more than being compliant with the post-transplant medication, but also being willing to look after oneself. A patient can be compliant through the strict scrutiny of family members and the medical workers, or he/she can be compliant because he/she is emotionally independent enough to be able to and willing to take good care of him/herself. Emotional independence was also raised as one of the four aspects of the 'quality of life' criteria; it was referred to as 'self-care'.

"Some patients are not interested in looking after themselves. They go on to lead an unhealthy lifestyle...to have a heart transplant is like to sign a contract. The contract is to look after yourself...help us look after yourself."

Assessing the overall psychological suitability of the patient is not only a job for the psychiatrist, but that of the surgeons and the social workers. And this is done at NHC not only at the pre-transplant stage, but also at the post-transplant in the form of the patient support group. The NHC does this because it is believed that such criteria will require a lot more than psychological scientific testing.

Finally, personality trait could be taken as a whole, in-itself, without the evaluator even bothering to break it down into the components. Personality trait then becomes an eclectic product of collapsing things like social and moral worth; it resembles an implicit form of discrimination. Simply put, and articulated by TxH:

"...But if the patient is a drug addict and an ex-convict, most of the time we are concerned with the personality trait of the person. We reject them because of that, not because of other reasons (I had earlier asked if social worth was the reason). But I think that sometimes we must be careful to pay too much attention to these things. All these are unwritten biases; we don't put down in black and white. We don't say that if he's a soldier he'll have a better chance. But no matter what you say, there is always something in life you look at.

The interview with TxH informs one that many of decisions are actually based on ethical judgments. Even though the NHC is a medical organization, the way it allocates hearts requires more than medical guidelines; medical rationality alone simply cannot tell the physician how best to select patients for a new heart.

The criterion of personality trait is not a formal one that is made public, yet it plays a very important role here. It can be understood as a rather holistic notion that encompasses many values held by the decision-makers. One can also detect an element of moral worth within the criteria; perhaps ex-convicts are discriminated while drug addicts are seen as a burden to society. What is sociologically interesting

here is that a national organization like the NHC, with its small numbers of decision-makers has the freedom to create its own admission and selection criteria based on its own ethical or political value. The NHC does not appear to be as utilitarian as Programme L. From the way NHC utilizes and justifies the admission criteria, it expresses a much more deontological commitment towards specific groups of patients. This is contrasted to the situation in the U.S., where the favoring of specific groups of people is not a widely supported criteria; it is used by only 27% of medical directors in the study conducted by Kilner (1990: 42).

II. Selection from the waiting list

The selection of patients from the waiting list would include many of what TxH called 'soft points'. These criteria include:

- 1. Personality trait
- 2. Social support
- 3. Waiting time
- 4. Quality of life

As mentioned earlier, personality trait can also be used at the selection stage, given that some patients manage to 'slip past' the admission stage. However, this criterion is more or less bundled into that of the Quality of Life (QOL), which also

includes the notion of social support. However, the QOL, unlike personality trait, has got nothing to do with personal responsibility for the illness. The presence of social support is used as an indicator of how much post-transplant care the patient can possibly get. And indirectly, the overall QOL 'score' for the patient can also increase with the presence of social support.

Unlike the way it is done at UNOS, waiting time is not one of the formalized criteria in the system of ranking used in prioritizing patients on the waiting list (See Appendix 3). Waiting time will always be secondary to the need of the patient; it is not an absolute indication. As TxH put it,

"If you are getting sicker and sicker, you might be waiting for just one month, we'll transplant you. Unless everything else is equal, then we transplant the guy who has waited quite long".

The prioritizing of a sicker patient over one who has waited for a long time reveals the greater importance of urgency rather than equality or desert to the programme. Just like the liver transplant programme, need still overrides other considerations. Waiting time is only used as tiebreaker when "everything else is equal", which is a rather rare instance. The issue of waiting time raises another question; that of an optimal time for operating on the patient. In the words of TxH:

"The most difficult thing in heart transplant is to decide the optimum time to do it. We don't want to transplant the patient when they are very sick, when they are getting into end-stage organ failure where we are faced with that uphill task trying to combat all those dysfunctions after transplant. We also don't want to transplant them too early, because doing a transplant is actually replacing a diseased organ with another diseased organ. So it's very important to find an optimum time."

In the case of the NHC, the optimum timing problem reveals a contradiction that exists between trying to increase the lifespan of the patient, and saving the life of the patient; i.e. between success and need. In addition, it is difficult to predict just how long a patient can survive after the transplant. In fact, in a study in the West on physicians' assessment of a patient's post-transplant prognoses, physicians came up with huge variances of the length of benefit the patient could possibly gain (Pearlman et al, 1989: 425). The dilemmas that physicians face in the particular case of determining optimum timing will be elaborated later.

Quality of Life

The QOL is understood by the NHC as being synonymous with the 'meaning of life'. The significance of the QOL criteria is that it is more important than the quantity of life. In the words of TxH:

"To be honest, now in operations, we don't look at the success or failure. Life and death are long gone as the arbiter that we use to gauge something. Eventually the important thing we want to look at is

the quality of life. Like if you have a good quality of life then obviously it is worth taking the risk. Organ transplant, no matter what it is still a very risky operation. The older you get the sicker you are the higher the risk. You know eventually you can have a healthy organ but if you do not have a meaningful life, then that's also no point. I think that is important. So what we eventually want to look for is the quality of life."

QOL was mentioned when the interview got to the issue of the 'benefit' to the patient. The concept of 'success' was often associated with long-term prognosis. Because of this emphasis, it had been assumed that 'benefit' meant long-term prognosis, which had also been assumed to refer to the post-transplant lifespan. The emphasis on QOL was only revealed when TxH was asked for a definition of the concept of 'benefit'.

According to TxH, the QOL has four aspects, each of which has some implications for the types of indicators that the decision-makers look for in selecting patients:

- 1) Ability to contribute to society
- 2) Ability to enjoy leisure
- 3) Ability to maintain normal human relationships
- 4) Ability to look after oneself

If patients were to be selected based on the ability to contribute to society (a social worth criteria), then the older patients would be excluded. In fact, it was explicitly

admitted that the younger patient would be preferred in many cases. The other aspects of QOL would also imply that if one were to be an inactive person, he/she would not get a new heart because he/she would not be participating in a lot of 'meaningful' activities. Thirdly, just like the social support criterion, the preferred patient would be one who has a good social support system, not only for the sake of post-transplant care or to maintain compliance, but simply because humans "are societal", that humans, in the eye of TxH, are necessarily social animals. Finally, the ability to look after oneself, as was mentioned in the section of personality trait, would exclude those who are not interested or disciplined enough to engage in self-care. I have below, the exact words of TxH in his description of what QOL constitutes:

"First of all we would want to try to get them back to contribute to the society. So it's the younger patient that we would hope to transplant. You know when we look at a person actually there are only four aspects. One is to be independent. To be able to work and earn a living, supporting myself and my family. The other aspect is your leisure. You want to be able to enjoy your life, and not work your whole life. Life is more than just work. The third aspect is to maintain a normal good relationship...if you're married, with your spouse with your children, I think it's important. Establish a normal relationship with people, I mean we are societal. fourth aspect is, no matter whether you are married or not, you must be able to look after yourself. Self-care is very important. I think if you ask what the purpose of living is, it's like that. I believe there is

more...psychological, religion. I think the psychological part is also very important. Often we only concentrate on these four aspects, a lot of time we forget about our psychological requirement. That's the reason why we have this patient support group. I think this is life. When a patient is sick and one of these aspects is interrupted, so when we say we want to get them back to work, have meaningful relationship with wife, play with children..."

In the U.S., the quality of benefit criterion is the most broadly supported amongst all the criteria (Kilner, 1990: 152) in the allocation of scarce medical resources. In fact, 97% of medical directors consider it relevant to the selection of patients. This criterion receives support in many countries in the world as well (United Nations, 1975: 31; Schwartz and Grubb, 1985: 24), and for organ transplants, a qualitative nature of post-transplant prognoses is taken seriously too (Task Force, 1986: 87; Jackson and Annas, 1986: 119). Besides the quality of life of the patient, 72% of the U.S. public have argued that a higher quality of life of patients increases their social worth, allowing them to make greater contributions to society (Evans and Manninen, 1987: 3). The main debate surrounding the usage of quality of life rather than quantity of life is the issue of whether the value of lives is different because they are experienced differently. The proponents of the QOL criterion argues for a qualification of life in terms of the happiness and meanings derived from it, while the opponents (usually those in support of the criterion of the lifespan of patients) argue that one should not make a distinction as all humans should be treated alike (Kilner, 1990: 153-156). As one can see, this is an ethical

debate, and therefore, the NHC's decision to pay that much attention to the criterion is an ethical decision.

Other selection criteria

Besides the above different ways in which one selects patients from the waiting list, there are other miscellaneous issues that have implications on the selection processes as well. They are firstly, the issue of retransplantation, and secondly, the prestige of the surgeons involved.

The problem with retransplantation is two-fold. Firstly, it is a medical problem as explained in the previous chapter. The second problem is an ethical one, and it has to do with fairness. Given that a patient already has a first transplant, should not a new organ go to someone else who has not gotten one? This is another dilemma that the decision makers have to face (I have also discussed this issue in the chapter on liver transplants). I shall talk about dilemmas in a later section.

The second possible issue that might have implications on the selection criteria is the effect of transplant statistics on the prestige of the surgeons or the programme. Although the NHC did not mention that this is something that they would consider as a possible principle for allocation, TxH did mention the existence of this consideration. It was pointed out that:

"Sometimes for certain transplant hospitals, you see hey their results are all very good. If I pick and choose all my patients and don't operate on sicker patients of course I'll have very good results. And so people look at it and say hey how come your patients are all very good patients. Like the cases that we do, people do not want. Those are the patients who are half dead...there is always a certain amount of risk, we must risk stratify. What kind of patients are we doing? So looking at the survival figures, by itself it means nothing. Sometimes we see that the mortality rate is higher, it doesn't mean that you're a bad doctor...these are the issues one has to consider."

The above paragraph shows that besides medical and ethical considerations, political or economic considerations are possible principles used in organ allocation as well. Though allocation of organs is an ethical issue, it does not necessarily mean that the criteria or considerations are ethical ones only.

Hearts, like livers, come in a variety of quality. The heterogeneous nature of donor hearts means that a matching system between particular hearts and particular patients exists. Matching uses primarily two medical criteria, they are:

- 1. Blood group typing
- 2. Human Leukocyte Antigen (HLA) matching

Research has shown that HLA matching is not a strong guarantor of good prognoses for organ transplants (Sutherland, 1992; Ferguson, 1988; Terasaki, 1995;

D'Alessandro, 1995). This is due partially to the advancements in immunosuppressive medicine, which means that rejection of new organs can be well managed even with HLA mismatches. The conventional HLA matching process usually looks at the six main antigens, the NHC, however, only look at four antigens.

What is important here is that even though a potential recipient has an HLA mismatch with the organ, they are not always rejected; it is not an absolute contraindication. However, HLA matching has a primary function in finding out if the recipient has already pre-formed antibodies against the donor organ. The centre believes that if that is the case, the organ will encounter intense rejection. For cases where pre-formed antibodies are not detected, the NHC finds it acceptable that there are two mismatches amongst the four. Though immunosuppressive medicine is effective at present times, TxH argued that the body adapts to such treatment, and thus requires less of it. This also means that the body starts to tolerate the foreign organ after some time as well. TxH believes that HLA matching serves to better ensure long-term outcome because the more matches there are, the better the body tolerates the organ. This emphasis on long-term outcome would however, contradict the issue of the need of the patient. I shall devote the last section in this chapter to the conflict between need and success.

Other matching methods

Unlike that which is done at the liver transplant programme, an age-matching system does not exist. TxH pointed out that since 1999, UNOS has adopted the

age-matching system, where younger organs are given to younger patients (age below 18 years old). Given that younger organs are healthier, younger patients are actually favoured in the UNOS system. At the NHC, age matching will be difficult to administer because of the small number of organs procured. In its place, organs of lower quality are matched with sicker patients. Sicker patients who are given such organs are usually those, according to TxH, 'who we know are not going to make it anyway'. Giving marginal organs to these patients

'Gives them a chance, at least there is slight hope...a little hope is better than no hope'.

This shows the utilitarian leaning in dealing with matching organs, utility not in terms of the number of years the organ or the patient survives, but rather, the number of lives that can be saved. This is because, if the marginal hearts are not used, they will go to waste. However, lack of age-matching might be due to the small number of organs procured each year, and not because the centre is not concerned with maximizing the lifespan of the new hearts or the patients.

Comparing the heart transplant programme with that of the liver transplant programme, one can see that the former tends to be less concerned with maximizing the utility that the organ can bring, than fulfilling certain ethical demands. The NHC does not attempt to medicalize its patient selection criteria as much as Programme L. Given the many different ethical and idiosyncratic judgments it makes of patients, the NHC does represent a very good example of what Elster (1992) talks about in his *Local Justice*, that local centres to have a lot of autonomy in their decisions about

how goods should be allocated. A similar situation is found in Germany, where allocative decisions are highly discretionary. Every centre has the power to develop their own policies or that physicians are simply left alone to make their own decisions. In addition, the process of organ allocation are not made immediately known to the public (Schmidt, 1998). From comparing the list of admission criteria that NHC provided during the interview and what was found out during the interview, one could see the lack of publicity about how hearts are allocated in Singapore as well. The NHC is virtually left alone to decide how it is done.

III. Inconsistencies and Dilemmas: ambiguities in organ allocation

All the above documentation shows us the many ambiguities within the organ allocation process. These ambiguities are expressed in the various inconsistencies, dilemmas and compromises that are encountered in the decision-making processes. The previous sections have shown that there are four important phrases in NHC patient selection criteria that are used quite differently. They are:

- 1) Success: saving the patient's life in view of certain possible risks
- 2) Long-term prognosis: quantity of life
- 3) **Benefit**: quality of life
- 4) **Need**: imminent death

All these four are not totally compatible with one another. As mentioned earlier, a common moral conflict exists between the general conceptions (not only as understood by NHC) of need and success. In this case, the conventional conception of need would refer to, at NHC, the imminent death of the patient, while the

conventional conception of success refers to success, long term prognosis, and benefit.

<u>Inconsistencies:</u>

From the interview with TxH, there was a constant emphasis on the long-term outcome of the transplantation. In the initial stages of the interview, it seemed as if the contraindications used at the admission stage were intended towards lengthening the patient's life. Yet, it was later pointed out that the need of the patient would always be prioritized over the long-term outcome. This was again contradicted when it was admitted that it is the QOL that is the arbiter of patient selection criteria.

Dilemmas:

Besides the inconsistencies, a prominent dilemma exists between the principle of need and that of success. This dilemma was evident in three practices which I had mentioned earlier: HLA matching, retransplantation and optimal timing.

1) HLA matching was done for the sake of the long-term outcome of the transplant. This means that success as long term prognosis is emphasized here. However, since HLA mismatched patients are not rejected, this only means that the emphasis on long-term outcome can be compromised by the emphasis on the need of the patient.

If a patient with HLA mismatches (not pre-formed antibodies) is dying, the patient will probably be given a new heart.

2) The issue of retransplants reveals the dilemma between emphasizing need as imminent death or success as risk-benefit ratio. One of the most common justifications given for retransplants is the commitment to the patient, as exhibited by Programme L and one particular example from Pittsburgh where a single patient was given five different organs (Elster, 1992: 148). For the NHC, which has done one retransplant, retransplants are not favoured over first transplants because of the higher risk involved. A patient who has rejected the first graft would be significantly weaker and sicker, and therefore would probably need (the patient is more likely to die) the second graft more than another. Deprioritization of retransplant patients therefore contradicts an earlier emphasis on need, where

"Most important is the need, not the success. I mean we all like to have a good success rate, but we are constrained by our environments. It's not up to you to choose. You just have to do what is necessary for the patient, eventually; it's the patient that counts."

3) The clearest indicator of this need-success dilemma lies in the determination of the optimal timing for a transplant operation for a particular patient. If a patient is transplanted when he becomes sicker, one is doing it based on the principle of need. However, the sicker patient would probably have a worse prognosis than a healthier one, and this compromises the length of benefit. On the other hand, if a patient is transplanted early, the length of benefit would not be optimum either because the

patient could be kept alive for longer periods with medication. In other words, if, for example, a patient has been on the waiting list for one year, and that he can survive for another five years with a new heart, his extended life would have been a total of six years. However, if he is transplanted with a new heart after being on the list for one month, and he can survive for another 5 years with the new heart, his extended life would have been a total of only 5 years and one month.

Compromises:

Matching marginal organs with sicker patients is a form of compromise made between the principle of need and that of success. By giving these patients marginal organs, one manages to save them from imminent death, but will not prolong their lives by much. If one were to give sicker patients healthier organs, the patients might not last as long as those healthy organs could offer, and this could deprive healthier patients of good organs as well. Therefore, in order to make full use of those healthy organs, and to give healthier patients better prognoses, healthier patients are given healthier organs. Success then becomes the guiding principle here. In other words, matching marginal organs with marginal patients fulfils the principle of need, matching healthy organs with healthy patients fulfils the principle of success.

Conclusions

The question is, how then, does one choose between the principle of need and the principle of success? How does one actually establish the optimal timing for an operation? Given that it is not just a matter of extending one's life, but also includes the QOL, how does one make the decision as to when and who to operate on? Whatever is done and however it is done, one can see that medical criteria have a very limited role to play here. All the inconsistencies and dilemmas show that such decisions are based on anything but clear-cut medical technical criteria. Principles like need, success, benefit, and public relations are hard to be reconciled. Moral, political, economic and other valuations all come into the picture. As one surgeon puts it, 'it's all unwritten biases'.

Chapter 7

The Selection of Patients for Kidney Transplants

This chapter presents the allocative issues within kidney transplantations. Kidney transplantations differ from that of both livers and hearts because of the availability of dialysis as an alternative treatment for ESRD. Unlike liver dialysis, kidney dialysis allows the patients to survive almost indefinitely. Kidneys differ from hearts because only one kidney is necessary for survival, therefore, like livers, living-donor kidney transplants are possible.

<u>Introduction to Programme K:</u>

The kidney transplant programme at SGH is linked through a computerized point allocation system to the NUH kidney transplant programme. The point allocation system is based partially on the UNOS system, but to what extent it differs I have not been able to ascertain because how points are allocated to patients on the waiting list is classified information withheld by the MOH. The waiting list operates at a national level while the more specific selection and surgical procedures are done at the local level (i.e. the transplant centres). There were 666 patients on the waiting list for kidney transplants by the end of year 2003. Each year, SGH gets approximately 80-100 live donors and 100 cadaveric donors while NUH gets only 40-60 live donors. From these pools of donors, only about 25% result in successful transplantations. This means that most of the patients stay on the list and compete

with new patients being added on each year. Of those on the waiting list, five of them pass away each year (The Gift, 2002).

It was claimed by TxK, a kidney transplant surgeon, that Programme K has a relatively high success rate (though TxK did not supply the exact statistics). Measured in terms of half-lives (the time needed for 50% of transplanted organs to cease functioning), the half-life for cadaveric transplants is 20 years in Singapore, while in the United States, it is about 12 years and as for the world average, about 7.5 years. In addition, Programme K has a good funding system, where patients are subsidized for life for their treatments while in the U.S., they are only funded for 4 years. Finally, the average age for transplantation is from 40-45 years old.

The unique mechanism used in Programme K is the computerized point allocation system that is applied nationwide. The system allocates points to patients in accordance to various criteria like age, waiting time (usually about 6-8 years), HLA matches, etc. and according to TxK, that after running the patients through the computer, they are usually left with about 30 patients. This means that the selection process compares this group of patients against one another, using again, the point allocation system and in addition, other non-computerized methods as well.

Patient selection philosophy

Programme K is based upon a set of what TxK calls "philosophies". The programme approaches the issue of the admission and selection of patients with three main attitudes:

- 1. Best survival (success)
- 2. Justice
- 3. Sympathy

And all these three are incorporated ("we try to combine them together") into the computerized point system, which, according to TxK, gives "objectification to the whole system...it will weigh and look at all these [medical] and the social criteria". Therefore, the computer does not only apply the medical criteria, but other 'social criteria' as well. According to TxK, the most important criteria are the medical ones, for they provide the best survival. This either reflects a medicalization attempt or a utilitarian attitude. An example of a medical criterion would be the contraindication of having ischemic heart disease, which is seen to shorten the lifespan of the new kidney. This means that best survival or success is measured in terms of the quantity of life of the kidney and not the patient. However, there are numerous other caveats that stem from this set of philosophies; I will elaborate on them further in the following sections.

I. Admission into the waiting list

As mentioned earlier, the waiting list for kidney patients operates at a national level. Below is the list of the criteria that are used:

Criteria to be on the transplant list (NKF, 2002e)

- Be below 60 years of age
- No cancer or history of cancer
- Not Hepatitis B antigen E positive
- No active or chronic infections
- No active auto-immune disease (SLE)
- No heart disease
- No long-term mental illness
- No history of stroke
- No untreated urinary reflux or bladder problems

Programme K, like the NHC, does not make its patient selection criteria immediately available to the public. The above list of criteria was obtained from the NKF rather than the transplant programmes. Just like the admission procedures used for liver and kidney transplants, the criteria used at this stage can be differentiated into either absolute or relative contraindications. But this is only done in practice, not on paper.

As seen above, the admission criteria focus on contraindications rather than indications. This means that patients are 'filtered off' from getting a new organ rather

than being 'let onto' the waiting list. This makes the selection process much more exclusivist, which is not surprising given the long waiting list and the low procurement rate. The greater the discrepancy between demand and supply, the stricter the criteria tend to be. According to Kilner, one solution to the scarcity problem is to tighten the criterion of medical need until the number of patients who qualify for the resource match the resources available (Kilner, 1990: 14). As admitted by 85% of US kidney dialysis directors, an age criterion would be employed under conditions of greater resource limitations (ibid: 78) while only 10% use the criterion at the time of the survey. This serves as an example of how a more exclusivist contraindication is employed to deal with the scarcity problem.

The only clear indication for kidney transplant is that the patient must be suffering from ESRD. Another possible reason why the emphasis falls on contraindications rather than that of indications is because even patients suffering from ESRD can be left on dialysis for a long period of time, they are probably not considered 'urgent' cases unless as TxK puts it, the patient 'can't dialyze anymore...he has no more blood vessels'. According to TxK⁷,

"... with only transplanting 30 people out of the 100 we get every year, and if you allow 130 onto the waiting list but still do 30 every year, your backlog goes up too. So there must be a practical approach and balance, since the numbers of kidneys are not increasing... it's artificial I agree, but it's the easiest".

Just like the NHC, Programme K does not formally differentiate between absolute and relative contraindications. It was only done in actual practice. To make things clearer, I shall classify the above criteria into absolute and relative contraindications as applied by the programme:

Absolute contraindications:

- 1. Age
- 2. Cancer
- 3. Heart disease
- 4. Auto-immune disease (HIV infection)
- 5. History of having stroke

Relative contraindications:

- 1. Hepatitis B infection
- 2. Chronic infections
- 3. Mental illnesses
- 4. Urinary or bladder problems

Besides the above, TxK added that for those who have opted out from the Human Organ Transplant Act (and for Muslims, those who have not opted in), they will get 60 debit points⁸. Though this means that patients who have objected to organ donation will not definitely be denied a new organ, the law is strictly adhered to and henceforth rather 'absolute' in its application. Besides the provision being legally mandatory, TxK sees it as a form of retributive justice, as "one who gives shall receive". The law is after all, not detached from the values of a society.

The Contraindications

Programme K differentiates between physiological and chronological age as well, but only applies the chronological age limit of 60 because it is a 'concrete thing that is easy to manage'. The age limit of 60 is strictly adhered to, since the computer excludes those who are beyond this age. Though the application of the age criterion is very strict, TxK acknowledges the various different ethical arguments for and against the rationing of organs using the age criterion. Age, like any other criterion, is recognized as being imperfect, but applied as an indicator of success and for the sake of practicality. It is imperfect, for example, when used to allocate goods based on desert, which is described as 'an emotive' principle. As pointed out by TxK,

"What makes us say that a 51 year old should not get a kidney isn't that wrong as well? Aren't they the elderly who have contributed more to our nation? Isn't it equally justified? More justified than the 20 year old who has not done anything? Isn't that an emotive issue too?"

TxK was frank in admitting the many 'caveats' that surround the application of age as an absolute criterion, illustrating the point by pointing out that "there have been diabetics at 50 who have aged a lot more than one who is 65". Unlike the medicalization practiced by the other decision-makers, TxK seems a lot more reflexive and aware of the principles behind the justifications for various criteria.

And for using chronological age rather than physiological, it was admitted that it was done for the sake of success and ease of management.

In line with the criteria used by the other two programmes, Programme K uses the presence of auto-immune infection as an absolute contraindication. The example of an auto-immune infection that was highlighted was HIV infection. As mentioned earlier, research show that HIV infected patients do as well as those without, but it is nevertheless used in the kidney transplant programme to guarantee success.

Mental retardation used to be an absolute contraindication, but according to TxK, they have never managed to quantify mental retardation. It is indeed an exclusion criterion on paper, but it is not practiced. It was suggested during the earlier days of the programme, that the cut off point for admitting mentally retarded patients into the waiting list be set at the IQ of 80. However, TxK pointed out that there was a patient who had managed to preserve a functioning new kidney for 12 years even though she had an IQ of 80. Ultimately, mental retardation is only relevant as an indicator of compliance, "if they can be compliant, if they can bring up their children... that is the key issue...all the other issues pale in comparison". TxK believes that if one is able to stay on dialysis, one would have enough intellect to stay alive and survive the post-transplant treatment. As mentioned earlier, using compliance as a criterion faces the problem of measurement. TxK had pointed out that compliance could not be measured by one's level of IQ. Instead, compliance to TxK, is a very controversial yet important criterion in the programme. I will pay more attention to this criterion later.

Besides the usage of certain objective criterion like IQ to determine compliance, the role of the physician who happens to be in charge of the patient plays an important role as well, for the physician would have to judge and advise whether the patient could be sufficiently compliant to undergo the transplant. This aspect of the admission stage is what TxK calls 'physician advocacy'.

Finally, just like the other two transplant programmes, the kidney transplant programme prioritizes Singaporeans and Permanent Residents over foreigners. The organs that are procured locally are not meant for foreigners, who will only be operated on should they provide their own live donors. Between Singaporeans and Permanent Residents, there is no difference in priority.

II. Selection from the waiting list

The role of the committee and physicians

According to TxK, the selection of recipients from the waiting list is undertaken by a committee (even though it was claimed that there is always a point difference between any two patient) that comprises of one nephrologist, non-kidney specialists and lay men. The Ministry of Health appoints all these people, and they rarely get called upon to exercise their duties. In fact, TxK pointed out that the committee had actually assessed only two patients, and both of them received new kidneys. The committee thus essentially deals with ties between cases.

TxK pointed out that the computer does most of the work of selection. TxK's role is to suggest selection criteria that will be allocated points and fed into the computer. Besides having the back-up system like the selection committee, the choice of who gets a new kidney depends on the physician who happens to be on duty as well. This is the physician advocacy aspect. He/she has the authority to judge if the patient next in line to receive the new organ is suitable there and then to be operated on. For example, a patient running a fever might be seen to be unsuitable and henceforth have to have the opportunity forgone and be replaced by another patient – regardless of which centre (SGH or NUH) he/she is from. In addition, a committee called the Advisory Committee on Transplantation and Dialysis is responsible for analyzing patient selection decisions after the transplant has been conducted. The committee is made up of mostly lay people and few doctors, and they are responsible for judging the soundness of the decisions that had been made, and henceforth offer suggestions about how such cases should be dealt with in the future.

The selection criteria:

There are several criteria that are applied in the selection process, they are:

- 1. Compliance
- 2. Waiting Time
- 3. Urgency
- 4. Quality of life

5. Sensitization

6. Re-transplantation

As mentioned earlier, the admission criteria are represented by points and fed into the computerized system. Some selection criteria operate the same way as well, and only a few other criteria are not included in the point system. Those that are not included are: compliance, urgency and quality of life. This means that physicians and the committees are responsible for dealing with these three criteria on an ad hoc basis, for compliance, urgency and quality of life are not easily quantifiable. Unfortunately, how much points is allocated and how they are allocated to the above criteria, are classified information known only to the MOH and the transplant personnel.

Compliance:

It is claimed that the level of compliance is 'excellent' for patients transplanted in the programme because only those who are likely to 'keep their kidneys the longest' are transplanted. This means that success is defined as maximizing the functioning years of the organ. Compliance, to the programme, is understood in a rather complex manner. It is argued by TxK that an excellent degree of compliance depends on two factors. Firstly, because the patients understand that they only get one chance at getting a new kidney, most of them would take good care of it. Secondly, because of the long-term post-transplant funding scheme available (patients are funded for life), patients are encouraged and have the resources to continue taking care of the new organ.

Compliance is measured with the help of the psychologists, but it was not explained how exactly it was done. It was argued by TxK, however, that those who have not been compliant while on dialysis (35% of patients) will not necessarily be non-compliant for transplant. This is because kidney failure and dialysis treatment is a long-term 'tough' experience that usually lasts 6-8 years till the patient is transplanted. Non-compliance while on dialysis is due to dialysis fatigue, and therefore, compliance would be greatly improved at the post-transplant stage because patients would be grateful to be taken off dialysis. At this point, TxK appeals to the principle of justice to justify the argument, that one should transplant a patient before he/she becomes so non-compliant (while on dialysis) that he/she is no longer fit to be transplanted. The principle of sympathy was also used to support the argument that it is too punishing to take a patient off from the waiting list simply because he/she is not compliant or to penalize a smoker for having inflicted him/herself with various diseases.

Compliance, therefore, is not just used as a proxy for success; it is also used as a justification for not leaving patients on dialysis. This means that the decision makers (the psychologists and the committee) would need to define what exactly is the function of the compliance criteria in order to decide whether compliant or non-compliant patient should be given a new kidney. On the one hand, a compliant patient is seen to be able to gain better prognosis, but on the other, a non-compliant one should be given an opportunity (based on the principles of justice and sympathy) because he/she will likely be compliant after transplant (based on the principle of success).

The issue of compliance is regularly tied to the issue of self-infliction. Self-infliction is not an important issue for the kidney transplant programme because of the principle of sympathy – one should not punish self-inflicted patients. Yet, retribution was actually implied to be a course of nature, because, as pointed out by TxK, drug abusers tend not to be compliant on dialysis, and henceforth they will "weed themselves out". This means that one does not need to reject patients on the counts of desert, for self-inflicted patients will naturally weed themselves out. However, it was stressed that even if desert was an allocative principle, where "Singapore finds it hard to forgive [self-inflicted patients]...I don't see that as a criteria (TxK)".

One can see from the above the many different variables taken into consideration in the application of the compliance criterion. Compliance is not included within the point allocation system, therefore, it is not a criterion that can be measured and implemented objectively. In fact, TxK seems to imply that compliance cannot be judged using an objective criterion like IQ level. Even though it was admitted that Singapore, as a non-welfarist state does not forgive self-inflicted patients easily, TxK does not see and use that as a criterion in the programme. In fact, the programme tends to be more sympathetic compared to the NHC. This reveals the discretionary nature of the selection criteria, and the amount of power wielded by individual programmes and decision-makers.

Waiting Time

Waiting time is applied as a criterion for the sake of justice, according to TxK. Waiting time is given a 'major priority' because many medical problems have been resolved, therefore selection criteria now lean towards issues of fairness (justice). This reality is reflected in western countries as well, both in the U.S. and in Europe. The UNOS and the Eurotransplant network has moved from a utilitarian emphasis towards one more firmly grounded in fairness and it was observed (Scarce Medical Resources, 1969; Fox & Swazey, 1974; Schmidt, 1998) that newly established transplant programmes tend to be more success-oriented and moralistic because of the need to gain acceptance for their methods, or because of the need to protect scarce resources. The tendency is for the criteria to become less strict, and types of patients who were rejected in the earlier days are now allowed more opportunities to get those goods.

The maximum points allocated for waiting time is 10, but it has been increased to 20 (equivalent to 10 years on the list) because of active lobbying by TxK. This show the influence single physicians have over 'objective' criteria. It is claimed that 30 patients are left on the shortlist after having been run through the computer, and if there are any two patients with exact point similarities, waiting time is evoked as tie-breaker.

The problem with allocating more points to waiting time is that the longer a patient waits, the more points he/she gets but the worse his/her condition becomes.

TxK points out, however, that dialysis will have weeded out those with worse

conditions. This does not really address the contradiction but it does seem to imply something about the principle of desert. It appears that patients who are able to remain on the waiting list (while on dialysis at the same time) without getting sicker are actually rewarded with more points. This averts the contradiction because the deterioration of the patient's condition while being on dialysis is not entirely within the control of the patient, but the reward of waiting time points to those who stay alive assumes it is so.

The contradiction is apparent and it has been admitted to be real. TxK laments that if one were to look purely intellectually at patient characteristics, "any patient could do better...but it is important to have objectifiable criteria...without objectifiable criteria, how do you say?" The use of objectifiable, i.e. quantifiable criteria is then necessarily functional: organs are scarce and therefore they must be rationed. Without objectifiable criteria, rationing is impossible. Though it has been acknowledged that organ allocation criteria are highly ambiguous (from a purely intellectual point of view), the concern here is still the operationalization of any allocative principle, be it justice, success or sympathy.

Urgency

TxK believes that any allocation system must not operate in a punishing mode. Patients should not be denied organs because of self-infliction. And if patients are urgently in need of organs, they will be prioritized. This means that urgency or need always overrides others like success or waiting time. Urgency is defined quite clearly

here: patients who are unable to dialyze anymore are deemed to be urgent cases. Kidney dialysis requires the insertion of intravenous needles into the upper limbs of the patients, and after prolonged use, the veins are almost totally destroyed, so that the procedure is no longer possible¹⁰. These patients are then transplanted first. However, these patients must be medically suitable for transplants. Patients must again, pass through the absolute contraindications.

Quality of Life

Unlike the heart transplant programme, the kidney transplant programme attempts to and believes in the possibility of quantifying a patient's quality of life. Perhaps this is because of the large number of ESRD patients waiting for transplants, objectifiable criteria are more likely to be used for allocation. This makes the allocation system look rather confusing, there are some criteria that are not quantified, like compliance, yet there are others equally qualititative in nature but are quantified, like quality of life. Though TxK claims that the quality of life can be quantified, on closer inspection, quality of life simply refers to the nature of the life of any patient who fulfils the medical criteria. In TxK's own words:

"If they have no heart disease....how do you decide if somebody has no quality of life? Medical criteria: are they able to work? Are they able to do everything? If they can do everything then why don't they have any quality?"

TxK's definition, compared to the NHC's, is much more encompassing. Between the two centres, the latter tends to be rather moralistic and 'punishing' than the former. Perhaps, as argued earlier, older centres tend to be more liberal with the criteria. And given that kidney transplant has been around much longer, this trend reflects what has happened in the West.

Previously, the programme did have some form of quantifiable non-medical quality of life indicators. One of them was employment status, which was further classified into full or part-time employment or whether the patient is a student or a worker. This criterion was removed because of the perceived lack of justice. It was argued that patients do not have jobs because they are ill, it would then, not be fair to deny them a new organ because of their joblessness. In fact, by getting them off dialysis, it would help them get employed. In addition, housewives were not considered to be employed, and if the old criterion was still used, housewives would be de-prioritized. And that is not considered fair. This again, reflects the liberalization of criteria. However, one must not ascribe this to purely structural causes, but also take into consideration the influences of individual physicians as well. Apparently, many changes seen in the programme were suggested and lobbied by TxK as the director of the programme.

In addition to employment status, social worth criteria appear to collapse into the quality of life criteria. The programme used to consider whether a patient has dependent family members, but this criterion was removed because it was considered too 'impractical'. This is primarily because, as TxK said, of the difficulty

of trying to argue for the social worth of an individual. This, to TxK, is an ethical controversy that is difficult to come to any consensus.

Sensitized patients

Theoretically speaking, the possibility and intensity of rejection will be higher for sensitized patients. This medical factor has its implications on the selection criteria as well, depending on whether the criteria are based on success, justice or sympathy. If the criterion is based on the principle of success, sensitized patients would then be de-prioritized, which is what Programme K does. Sensitized patients are given a debit of five points (considered by TxK as not a serious penalty). Once transplanted, these patients are given more immunosuppressive treatments, but they are seen as having higher chances of experiencing complications. It was pointed out that in the United States, sensitized patients are awarded more points rather than less. This is seen to be illogical by TxK because as patients stay longer on the waiting list, they do not become more sensitized, therefore, there is no need to award them more points. In the past, patients need constant blood transfusions while on the waiting list, which increases their sensitization. With the new drug Erythropoietin that overcomes the need for blood transfusion, the level of sensitivity remains constant.

The U.S. system of awarding sensitized patients additional points differs in that it is not based on success, but rather on justice. Even though both sides know of the lower rate of success for sensitized patients, the two sides choose to emphasize on different principles of allocation. In the U.S., sensitized patients are awarded more

points because they are sensitized against more organs than normal patients, thus reducing their chances of receiving a suitable organ, and henceforth, something must be done to neutralize this disadvantage. The kidney transplant programme, on the other hand, simply looks at the outcome of the transplant.

Re-transplantation

Re-transplanted patients do comparatively worse because of their increased level of sensitivity. Programme K neutralizes the effects of higher level of sensitivity by making sure that re-transplant patients get perfect tissue matches with the donor. The difference between the U.S. and local kidney transplant programme in this case is that the former 'compensates' patients for their disadvantages while the latter 'compensates for' the patients' disadvantages. The U.S. system does it for the sake of justice while the local programme does it to ensure success.

Besides ensuring that re-transplant patients get perfect tissue matches, a couple of caveats are included as well. If the rejection of the first transplanted organ was due to a "technical problem", then the patient is not penalized, and waiting time clocked by the patient is considered to have begun prior to the first transplant. If the first transplant was a live donor transplant, then according to TxK, 'logically they never had a rejection'. Patients are then considered to have lost their organs because of other reasons like the lack of compliance. It is thus implied that live donor kidneys does not really get rejected. Patients like these are not penalized, because 'everybody repents, we must have a bit of forgiveness'. Patients like these will then

get a second organ from cadaveric donors. Thirdly, patients whose first donor was a cadaver, and that the transplant failed not because of technical reasons, then 'the second one is going to be terrible'. This is because, if the first kidney was from a cadaver, the tissue would have been less well-matched than that from a live donor, the failure of the transplant is then due to rejection. Then the second transplant will be less successful for the patient will have become more sensitized.

The above three cases can be understood in the following manner. For the first case, the patient is treated like a first time recipient except that the tissue matching criteria becomes more strictly executed. For the second case, the patient would be treated like any other first transplant patient because they are not considered to have rejected the organ, and therefore, there is no requirement to compensate for sensitivity. The third case is just like the first, the only difference is the cause of rejection, where the first is technical and the third is non-technical. However, given that the programme does not punish patients for self-infliction, it does not really make any distinction between the two cases then.

The principle of success then rules in re-transplantation. Re-transplant patients must achieve perfect HLA matches so as to counter the effects of increased sensitivity. Those who can keep the kidney the longest will get priority. The current expected functioning years for re-transplanted kidneys is around four years. However, for patients who are in need (those who cannot dialyze anymore), they will be given a new kidney even if the tissue matches are not good. Need always overrides success.

Kidneys are heterogeneous goods too. This means that they come in a variety of qualities. Besides blood-group typing, the programme practices HLA and age-matching. But programme K does not really allocate organs based on their quality, though it is acknowledged that there are indeed differences in the quality of organs.

HLA matching

HLA matching is defined as one of the top medical criteria, as high as the legal criteria, yet it was pointed out that tissue mismatches could be overcome by better immunosuppressive therapy. HLA matching has been used extensively as a criterion in the allocation of organs, both within the UNOS system and in Eurotransplant. What Eurotransplant does is not unlike UNOS; it matches the HLA of donors with recipients within a central database and allocates kidneys based on the best match (see Schmidt, 1998 for other caveats to kidney allocation in Eurotransplant). As mentioned earlier, HLA matches are hard to justify because research shows that they not necessarily guarantee better prognoses, and given immunosuppressive therapies available, HLA matching criteria probably serves other purposes. Compared to the U.S., Singapore has a relatively small pool of donors, and given that there is yet to be an organ-sharing network in the region, good HLA matches are hard to come by. HLA matching is then used because of its quantitative objectifiable nature, which allows its easy application, much like the age criteria used in Britain to allocate dialysis treatment to patients before it was funded by the state (Meissner, 1986: 6).

Age-matching

Age matching is done for a 'sociological' reason, in the words of TxK. Programme K maintains two waiting lists: one for adults and one for children. The sociological reason is explained rather deontologically as 'kids shouldn't be made to wait too long'. If the pediatric list is not maintained, children would have to compete with adults for the kidneys. In addition to the sociological reason, a minor medical reason was pointed out as well. Pediatric donors will be matched with pediatric recipients because small kidneys with small vessels will not reach adult size if given to an adult. But it was also acknowledged that there are counter arguments that kidneys do grow bigger (and the local programme has even transplanted a four year old kidney into a 40 year old man), so it depends a lot on the capability of the surgeon as well. If it happens that no pediatric recipient is waiting, the organ would be given to the physically smallest patient.

Quality of organs

The quality of organs is not taken into consideration while selecting patients because 'it's not practical'. This is because, in addition to medical, legal and sociological criteria, the inclusion of the quality of organs criteria would make the whole system too complex to handle. Once again it is the issue of workability.

According to TxK, to 'make a kidney work', there are three factors: donor, recipient and physician. The current system takes into consideration the recipient factor, and to consider the quality of organs is to add in the donor factor, which will 'make the working of the programme confusing'. However, it is still considered a good idea to match marginal kidneys with marginal patients because it will allow patients who would normally not be transplanted to be transplanted.

Besides the complexity, there is the issue of informed consent. This demands that every time a 'lousy kidney' is procured, one must ask the recipient 'do you want this kidney?' Patients have been asked whether they would prefer to receive a marginal kidney rather than wait for a good one to come by, and most of them chose the former, because "they don't know what's gonna happen to them if they wait". TxK had also explained that another reason why they do not exercise informed consent all the time is because the physician factor can possibly modulate the outcome of the transplant. Finally, it was also pointed out that it is difficult to predict just how long a marginal kidney will last. Therefore, if transplanting a patient with a marginal kidney can prolong his/her life, it will be justifiable to do so.

Conclusions

This chapter has highlighted the many similar and different issues encountered in kidney transplantations compared to hearts and livers. The main difference lies in the longer waiting list, which resulted in a greater need for having objectifiable criteria in the selection of patients. However, this does not mean that decisions are easy, though attempts have been made to make them easier.

As can be seen above, the programme adheres to three main principles: the principles of success, justice and sympathy. And like the liver and heart transplant programmes which have their own unspoken principles, these three principles contradict one another when they have to be implemented. Given the higher demand for kidneys, success becomes a dominant determinant of who gets selected for a transplant. However, just like that of the liver transplant programme, need always overrides success, but on the contrary, selection procedures for retransplant patients are much more complex than that of the liver transplant programme. Finally, the very uniqueness of the kidney transplant programme is its way of looking at waiting time. Unlike the liver and heart transplant programme that accords little emphasis to the principle of fairness, the kidney transplant programme allocates more attention to waiting time based on TxK's notion of justice.

What one can see in this chapter is not unlike that of the previous two, that no matter what principles the transplant programmes adhere to, many of the principles are firstly, non-medical and secondly, very difficult to be reconciled with one another. TxK was much more forthcoming and reflexive about the justifications behind the usage of indicators and contraindicators. Henceforth, unlike TxL and TxH, many decisions were not really medicalized away, but were acknowledged as being problematic but have to be made for the sake of workability.

Chapter 8

Conclusions

This chapter integrates the empirical data with the arguments put forward earlier. I will focus on the allocation process rather than the background of the transplantation scene in Singapore. My main argument in this paper is that allocative problems, which are non-medical ones, are resolved through medicalization, which serves functions both at an individual and at the social level. It helps the decision maker deal with the many ambiguities in the selection process, and it legitimizes an institution's function within the division of labor in society as well.

The field of organ transplantation is both a sphere of medicine and distributive justice. Both spheres possess their own rationalities that are used to solve their own problems. However, when both spheres exist within a single field, what rationalities are used to solve the problem of organ scarcity? Often, it is claimed by physicians that medical criteria are used to select patients for transplant. However, it is much more complex than that. This thesis seeks to show how exactly it is done, comparing the situation in Singapore with that of the West, and attempts to explain how the conditions of Singapore have influenced the decision-making process.

I. Corroboration of Theory with Evidence

I have argued and shown that after the admission stage, the number of patients on the waiting list exceeds the number of organs available. Selecting patients from this list would be unavoidable. However, the selection of patients from the waiting list is not a medical problem anymore. This is because the medical goal is to provide treatment to anyone who could benefit from and who need the treatment. It therefore does not tell one how to choose between patients who could all benefit from the treatment. The fact that these patients are allowed onto the waiting list shows that they could all benefit from new organs. How then, does one choose whom to get the organs first or last? Selection is not a medical problem then. It includes many non-medical considerations. However, decision makers often say that they use medical criteria to deal with these non-medical problems.

There are four basic steps that are necessary in putting forward my argument. Firstly, I have to show that medical criteria are not necessarily absolute, and that there are a lot of ambiguities involved. Secondly, I have to present those criteria that are non-medical in nature. This is followed by showing how complex and confusing the selection process can get, through revealing the many inconsistencies, dilemmas and compromises. Finally, I shall present how the complexities are simplified through trying to use medical criteria in selecting patients.

Medical criteria do not always yield consistent results. As I have shown earlier in all three chapters in liver, heart and kidney transplantations, that strict absolute contraindications, for example, HIV infection, do not always result in better prognoses in patients. Other controversial absolute criteria include age, which again, have been shown to have no causal relationship with the prognoses of the patient. And finally, alcoholics also yield as good prognoses as non-alcoholics. These three examples reveal that there is a significant amount of disagreement and controversy surrounding the application of such medical criteria, and henceforth, the decision to

use them is very much a decision made by the local transplant centres based on their own values or preferences rather than an adherence to some objective medical knowledge.

As presented in the first chapter, a medical criterion ensures the certainty of outcomes, in which these outcomes benefit all who can benefit from them. Given this definition of a medical criterion, non-medical criteria are not based on scientifically verified probabilities and are concerned with the benefit of some categories of people and not all. Medical criteria can usually be used only at the admission stage and not the selection stage. The list of non-medical and socio-psychological criteria has been shown in all three chapters on livers, hearts and kidney transplantations. I will re-present those criteria here again, and also reiterate what the underlying principles of these criteria are.

Medical criteria, as agreed by ethicists and medical practitioners, should fulfill the need for and provide benefits to patients. However, notions like 'need', 'success' and 'benefits' can be interpreted quite differently. And this allows decision-makers much leeway in choosing and justifying what 'medical criteria' to use in their transplant programme. Success can mean the expected long-term outcome of the operation or a risk-benefit calculation. Benefit can mean quantity of life or quality of life. Success also underlies the socio-psychological criteria used, where compliance and social/emotional/financial support are seen as important for the post-transplant care of the patient. The post-transplant welfare of the patient is measured in terms of the concept of benefit, which can also be quantity or quality of life. Finally, non-medical criteria are based on a variety of principles. Some are

grounded upon desert, like social worth, moral worth, and self-infliction. Others do not really have a clear principle, like cases of discrimination against certain types of people (older people, drug abusers, etc.). And finally, the more deontologically based 'thoroughness' ethos that binds medical professionals to the retransplant patients.

Allocating organs is a difficult and complex process, as can be seen in the inconsistencies and dilemmas that are encountered in deciding which patients are to be transplanted first. The process includes many different variables of different nature: from political, economic to ethical considerations. It would be almost impossible to take into consideration all possible variables and make a clear and easy decision.

The most common inconsistencies and dilemmas faced revolve around the concepts of need, success, benefit and outcome. They can all be defined and used differently, and they all depend on the different emphases on particular principles. Ultimately certain compromises have to be made, and they are often difficult. The most important thing that has been shown is that these dilemmas are not medical ones, but are due to the very personal or institutional values that are held. It is these values that guide the selection of patients, not objective scientific medical ones.

Finally, the medical rationalities that are used to simplify and solve the many non-medical problems can be seen in the numerous examples given on how medical justifications are used. This trend is shown in the regular claims made by various decision makers that medical criteria are used in the selection of patients.

Medical terms are often evoked to justify non-medical decisions. Because organ allocation is in both the sphere of justice and that of medicine, interests and types of rationalities collide. However the collision of rationalities is dealt with, both the institutions and the individuals benefit from operating within medical rationalities because medical rationalities have a seemingly objective nature which allows physicians to preserve their authority and to make the solving of the organ scarcity problem easier.

Medicine is seen to have a certain objectivity and neutrality to it, not only because it is a science, but because of the objectification of criteria that happens in institutions as time passes (Schmidt, 2002: 2). The presumed objectivity of criteria results in a felt imperativeness in using them, removing responsibilities from the user. All problems are then treated with these objectified criteria. Such criteria are treated as universal and neutral, in that they apply to all contexts and individuals, and they are not influenced by any form of subjectivities. This also means that medical practices are claimed to be the mere application of those criteria. This lightens the load on the decision makers as being responsible for anything that happens to those who have received or have been denied the goods involved, especially when organs are life-saving resources.

What I have gathered from this research and previous related ones is that:

1) Because the allocation of organs straddles both the sphere of medicine and justice, and because medicine has a seemingly objective nature,

- medical rationalities are often used to deal with all problems in distributing organs
- 2) Allocation of organs is not strictly a medical problem. Medical rationalities veil the various non-medical values that are the actual underlying principles behind the use of criteria.
- 3) The range of principles do not vary a lot from one transplant programme to another
- 4) What is different between one locality and another is the emphasis on certain principles rather than others

Like societies in the West, the division of labour in Singapore created sprockets of institutions that specialize in dealing with specific problems. The problems are alike for both Singapore and the West, where developed countries all experience rising numbers of cases of degenerative diseases resulting in organ failures. Secondly, the lack of donor organs is prevalent in both Singapore and the West as well, with Singapore experiencing a lower donation rate per million population. Even though Singapore is an Asian country, even though the decision makers are Asians themselves, problems of organ allocation are not resolved very differently from what was found in the U.S. and Germany. Decision makers do not differ in the range of principles they select from, but only in the different principles that they apply. However, even between the transplant centres in Singapore, much difference exists in the principles that dominate.

A few reasons account for the difference between the allocative procedures in Singapore and in the West. Firstly, Singapore, being an Asian country which began

its modernization much later, tends to be much more collectivistic and utilitarian than the West (Inglehart, 1995: 379-403). This can be seen in the more success-oriented nature of allocative principles. Secondly, transplant programmes in Singapore have been established later than that of the West, which also explains its moralistic principles (especially the heart and liver transplant programmes, which were established in 1990), specifically in their concerns with social worth (Schmidt and Lim, 2004: 2181). Finally, the non-welfarist nature of the healthcare system and the national ideology accounts for the emphasis on maximizing the value of organs, which is a utilitarian concern, and also being less forgiving towards self-inflicted patients (the NHC).

If one compares the three programmes, a certain pattern emerges in the principles that govern allocative decisions. The NHC which is as new as Programme L, deals with least number of organs available, pays a lot of attention to social worth and desert. Programme K, the oldest amongst the three, on the other hand, deals with a larger pool of organs, tends to be more liberal and concerned with using objective workable criteria. Finally, Programme L, falls in-between the other two, and it reflects a mixture of concerns with social worth and using objective medical criteria.

The above three sets of conditions: the Asian context, the age of the transplant programmes, and the healthcare philosophy play important roles in the principles and consequently, the criteria that are used in allocating organs. In addition, the size of the pool of donors/patients and the seriousness of the scarcity problems affects the degree of liberty or conservativeness of the principles as well. Decision-makers work within these conditions to create their own system of criteria and justifications to deal

with the organ scarcity problem they have at hand. And decision-makers do have a lot of power in creating those systems. This manner of allocating organs is similar to that in Germany (Schmidt, 1998), where every centre has the liberty to develop its own policy. And like Germany as well, many of the criteria used are not made public, and furthermore, public debates about the allocative procedures were unheard of both in Germany and Singapore (ibid, 60).

Perhaps just like the transformation in the U.S. from that of letting local centres decide on the criteria towards using more objective un-negotiable measurements, Singapore's organ allocation system will become less conservative and 'punishing', as exemplified by Programme K. It will be rash to attempt to predict what changes might occur to the allocative procedures, given the many possible transformations occurring in both medicine and society. For example, therapeutic stem cells research might potentially increase the supply of organs through the cloning of organs, or the plan to establish an organ-sharing network in Southeast Asia will raise many different political issues as well. These and many more variables will make further research into this topic in Asia worthwhile. Hopefully, this exploratory study undertaken in Singapore can provide a preliminary insight into the relationship between medicine, society and ethics. Whatever happens in the future, one can be sure that distribution of scarce resources like organs will always be a problem that cannot be solved by medicine alone.

Endnotes:

1

¹ There are two main types of dialysis: Haemodialysis and Peritoneal dialysis. Both of them require patients to be connected to an external artificial filter that cleans their blood. Heamodialysis requires patients to be attached to a machine three times a week, each time up to three hours, while for Peritoneal dialysis, patients they have to lug around a bag of liquid which carries the waste products filtered. Dialysis is therefore an unpleasant experience, and there are both medical side effects and disruptions to normal lifestyles as well.

² These moral conceptions can be classified into utilitarianism, deontology, retributive justice, and individual rights theory. Utilitarianism promotes the maximization of general welfare. Deontology or Kantian morality emphasizes the commitment to duties to other people. Retributive models of morality argues for equity (an Aristotelian concept), where certain acts deserve certain returns. Finally individual rights theory argues for equality, where all humans have the same rights to healthcare resources.

³ A similar system exists in Europe, named Eurotransplant and based in the Netherlands which handles an integrated lists of patients and matches their HLA with any available donor. Eurotransplant combines the waiting list of Austria, Belgium, The Czech Republic, The Netherlands, and Germany.

⁴ Kilner's study (1990) showed that 88% of his respondents from renal dialysis centres consider age as legitimate consideration and 92% of European renal transplant centers employ the age criterion.

⁵ According to Programme L, the mortality rate for the first year for those on liver dialysis was "100%". One wonders how mortality rate is actually defined here. Other sources have pointed out that patients can survive approximately a month on liver dialysis.

⁶ Elster (1992: 50) even pointed out that classical English moral philosophers like Mill and Bentham were the main pioneers of utilitarianism, and this could possibly account for the tradition of British utilitarianism in healthcare distribution. However, I find it to be stretching too far to apply this particular argument to Singapore's case, though the country used to be a British colony.

⁷ This concern was also voiced by a German surgeon (Schmidt, 1998: 56), who complained about giving too much hopes to patients were they to be admitted onto the waiting list while having slim chances of ever getting an organ.

⁸ Muslims who have not opted into the implied consent system are also given demerit points of -60. Rothman and Rothman (2003, 49) had pointed out that this is a discrimination against Muslims and that in no other transplant programmes in the world has this been practiced. However, others like Kliemt (2003) has argued otherwise for a club-model system of organ allocation, where priorities are given to those who have beforehand, contributed to the 'club' and have therefore secured membership and privileges. This paper does not attempt to say which is a better system, the question is left open for the reader to decide.

⁹ TxK pointed out that in the United States, post-transplant funding is only good for 4 years. This results in a lower level of compliance for American patients.

¹⁰ Sometimes in order to continue with dialysis, needles have to be inserted into other places like the back of the hand or even other parts of the body. The needles are quite formidable and hence the suffering dialysis patients have to undergo is increased significantly.

Appendix 1: The questionnaire

The questionnaire is separated into two sections, namely the concerns with admission and selection criteria, which can be referred to as absolute and relative criteria respectively. The questions would largely ask for the indications and contraindications for the filters imposed.

Admission

1) Age:

- 1. Do you have fixed age limits or do you take age into consideration in your decisions?
- 2. Are you aware that elderly patients fare quite well as shown in many instances?
- 3. If they are not considered on medical grounds, what other considerations are considered?

2) Nationality/residency:

1. Are these factors that are considered in the admission process, if yes, does it mean that foreigners who have lived in Singapore for a long time, but who are not PR, will not be considered even if they are in need. If so, why?

3) Social value:

1. Do you take the social worth of potential recipients into account? In other words, is the usefulness of the individual to society an important criterion? For example, a drug addict versus a soldier.

4) Personal responsibility for illness:

- a) Kidney failures are caused often caused by abuse of painkillers
- b) Heart failures are caused by excessive smoking
- c) Liver failures are caused by alcohol abuse
- 1. Do you consider such factors in the admission process?
- 2. Would you consider treatment for people with self inflicted illnesses? If yes, why, and if no, why not?

5) Alcoholism:

- 1. Are you aware that there are successful cases of liver transplantations for alcoholics who continue drinking after the surgery?
- 2. So is alcoholism a necessary contraindication for admitting the patient into the waiting list?

- 6) Imminent death:
 - 1. Do you include people who face imminent death?
 - 2. Do you consider their state of urgencies?
 - 3. Do you have specific ways to measure the levels of urgencies?
- 7) Socio-psychological:
 - 1. Do you make socio-psychological evaluation? In other words, are characteristics like mental illness, emotional support from family and friends, or emotional resilience of the patient important considerations?
 - 2. Do you have fixed measurements for these?
- 8) Compliance:
 - 1. What significance do you ascribe to this criterion?
 - 2. How do you measure compliance?
 - 3. Aren't there significant uncertainties in determining these indicators for compliance?
- 9) HIV:
 - 1. Would you consider them as candidates? If not why?
 - 2. Are you aware of studies which show that HIV patients can fare pretty well?

Selection

- 1) Do you have a fixed set of criteria which you apply consistently? For example, a point system, or do you decide on a case-by-case basis?
- 2) What are the criteria which you use in selecting recipients for specific organs, and how much weight do you attach to the various criteria?
- 3) What do you do when you get equal matching for HLA? What do you use as a tiebreaker?
- 4) What role do you give to waiting time?
 - 1. What is the range of waiting time for patients?
 - 2. What about those who have rare antigen patterns, what do you do with them? Do you have provisions in place for patients with preformed antibodies to receive organs? If yes, why, and if no, why not?

- 5) Do you make special provision for sensitized patients?
- 6) What other considerations do you take into account if you have 2 or more patients who are equal or almost equal in medical criteria? Would factors such as social responsibilities be taken into account? E.g. parents over non-parents, mothers over fathers, single mothers over mothers.
- 7) Is the quality of organs procured ever considered in the selection of recipients? In other words, do you try to channel better quality organ to younger patients and the more marginal ones to the elderly?
- 8) Is there a limitation to the age of the donor?
- 9) Re-transplantation:
 - 1. Do you conduct retransplantation, or do you give all patients only one chance. If yes, why, and if no, why not?
 - 2. If you are willing to conduct retransplantation, wouldn't this be unfair for those who have never gotten one before?
 - 3. Conversely, would not the abandonment of the patient who rejected the new organ undermine the trust between physician and patients?
- 10) How much weight do you place on patients' survival prognosis, both long and short term? Do you give priority to those with long term survival expectation or those whose death is imminent if not transplanted right away?

Appendix 2: Criteria for admission into the waiting list for liver transplants

The use of hepatic segments from living related donors is confined to a select group of patients who are in urgent need of liver transplantation. These include:

- Patients who would otherwise die on the waiting list
- Acute fulminant liver failure
- Foreign patients who are on the waiting list and are unlikely to obtain a cadavaric liver

Indications for liver transplant

- Cirrhosis
 - o Cryptogenic
 - o Auto-Immune
 - o Hepatitis C
 - o Hepatitis B, non-replicator (HBV DNA negative)
- Biliary Disease
 - o Primary Biliary Cirrhosis
 - o Secondary Biliary Cirrhosis
 - o Sclerosing Cholangitis
 - o Biliary Atresia
 - Hypoplastic Ducts
- Primary Metabolic Disease
 - o Alpha 1 Antitrypsin Defiency
 - o Wilson's Disease
 - o Tyrosinaemia
 - o Glycogen Storage Diseases
- Fulminant Liver Failure
- Hepatocellular Carcinoma
 - o i. 3 lesions or fewer & pre-treatment diameter < 8cm before embolisation
 - o ii. Single lesion size < 6 cm before embolisation

Absolute Contraindications

- Malignancy outside the liver
- Severe cardio-pulmonary disease or major medical illness
- Systemic Sepsis
- Medically or Psychologically unfit patient
- HIV infection

Relative Contraindications

- Age greater than 70 years
- Persistent Hepatitis B Infection (HBV DNA positive)
- Alcohol Dependence at least 6 months voluntary abstinence

Source: http://www.med.nus.edu.sg/sur/livertr.html

Appendix 3: United Network for Organ Transplants (UNOS) criteria for selection of heart patients

3.0 ORGAN DISTRIBUTION

The following policies apply to the allocation of organs for transplantation.

- 3.7 <u>ALLOCATION OF THORACIC ORGANS</u>. This policy describes how thoracic organs (hearts, heart-lung combinations, single and double lungs) are to be allocated to patients awaiting a thoracic organ transplant.
- **3.7.1** Exceptions. Unless otherwise approved according to Policies 3.1.7 (Local and Alternative Local Unit), 3.1.8 (Sharing Arrangement and Sharing Agreement), 3.1.9 (Alternate Point Assignments (Variances)), and 3.4.6 (Application, Review, Dissolution and Modification Processes for Alternative Organ Distribution or Allocation Systems), or specifically allowed by the exceptions described in this Policy 3.7.1, all thoracic organs must be allocated in accordance with Policy 3.7.
- 3.7.1.1 Exception for Sensitized Patients. The transplant surgeon or physician for a patient awaiting thoracic organ transplantation may determine that the patient is "sensitized" such that the patient's antibodies would react adversely to certain donor cell antigens. It is permissible not to use the allocation policies set forth in Policy 3.7 for allocation of a particular thoracic organ when all thoracic organ transplant centers within an OPO and the OPO agree to allocate the thoracic organ to a sensitized patient because results of a crossmatch between the blood serum of that patient and cells of the thoracic organ donor are negative (i.e., the patient and thoracic organ donor are compatible). The level of sensitization at which a patient may qualify for this exception is left to the discretion of the listing transplant center, and subject to agreement among all thoracic organ transplant centers within an OPO and the OPO. Sensitization is not a qualifying criterion for assigning a patient to a heart status category as described in UNOS Policies 3.7.3 (Adult Patient Status) and 3.7.4 (Pediatric Patient Status).
- **3.7.2** <u>Geographic Sequence of Thoracic Organ Allocation.</u> Thoracic organs are to be allocated locally first, then within the following zones in the sequence described in Policy 3.7.10. Three zones will be delineated by concentric circles of 500 and 1,000 nautical mile radii with the donor hospital at the center. Zone A will extend to all transplant centers which are within 500 miles from the donor hospital but which are not in the local area of the donor hospital. Zone B will extend to all transplant centers that are at least 500 miles from the donor hospital but not more than 1,000 miles from the donor hospital. Zone C will extend to all transplant centers that are located beyond 1,000 miles from the donor hospital.

3.7.3 Adult Patient Status.

Each patient awaiting heart transplantation is assigned a status code which corresponds to how medically urgent it is that the patient receive a transplant. Medical urgency is assigned to a heart transplant patient who is greater than or equal to 18 years of age at the time of listing as follows:

Status Definition

- 1A A patient listed as Status 1A is admitted to the listing transplant center hospital and has at least one of the following devices or therapies in place:
 - (a) Mechanical circulatory support for acute hemodynamic decompensation that includes at least one of the following:
 - (i) left and/or right ventricular assist device implanted; Patients listed under this criterion, may be listed for 30 days at any point after being implanted as Status 1A once the treating physician determines that they are clinically stable. Admittance to the listing transplant center hospital is not required.
 - (ii) total artificial heart;
 - (iii) intra-aortic balloon pump; or

(iv) extracorporeal membrane oxygenator (ECMO).

Qualification for Status 1A under criterion 1A(a)(ii), (iii) or (iv) is valid for 14 days and must be recertified by an attending physician every 14 days from the date of the patient's initial listing as Status 1A to extend the Status 1A listing.

- (b) Mechanical circulatory support with objective medical evidence of significant device-related complications such as thromboembolism, device infection, mechanical failure and/or life-threatening ventricular arrhythmias (Patient sensitization is not an appropriate device-related complication for qualification as Status 1A under this criterion. The applicability of sensitization to thoracic organ allocation is specified by UNOS Policy 3.7.1.1 (Exception for Sensitized Patients). Qualification for Status 1A under this criterion is valid for 14 days and must be recertified by an attending physician every 14 days from the date of the patient's initial listing as Status 1A to extend the Status 1A listing.
 - (c) Mechanical ventilation. Qualification for Status 1A under this criterion is valid for 14 days and must be recertified by an attending physician every 14 days from the date of the patient's initial listing as Status 1A to extend the Status 1A listing.
 - (d) Continuous infusion of a single high-dose intravenous inotrope (e.g., dobutamine >/= 7.5 mcg/kg/min, or milrinone >/= .50 mcg/kg/min), or multiple intravenous inotropes, in addition to continuous hemodynamic monitoring of left ventricular filling pressures; Qualification for Status 1A under this criterion is valid for 7 days and may be renewed for an additional 7 days for each occurrence of a Status 1A listing under this criterion for the same patient.
 - (e) A patient who does not meet the criteria specified in (a), (b), (c) or (d) may be listed as Status 1A if the patient is admitted to the listing transplant center hospital and has a life expectancy without a heart transplant of less than 7 days. Qualification for Status 1A under this criterion is valid for 7 days and may be recertified by an attending physician for one additional 7-day period. Any further extension of the Status 1A listing under this criterion requires a conference with the applicable UNOS Regional Review Board prospective review and approval by a majority of the Regional Review Board Members. If Regional Review Board approval is not given, the patient's transplant physician may list the patient as Status 1A, subject to automatic referral to the Thoracic Organ Transplantation and Membership and Professional Standards Committees.

For all adult patients listed as Status 1A, a completed Heart Status 1A Justification Form must be received by UNOS on UNetsm in order to list a patient-as Status 1A, or extend their listing as Status 1A in accordance with the criteria listed above in Policy 3.7.3. Patients listed as Status 1A will automatically revert back to Status 1B unless they are re-listed on UNetsm by an attending physician within the time frames described in the definitions of status 1A(a)-(e) above.

- 1B A patient listed as Status 1B has at least one of the following devices or therapies in place:
 - (aa) left and/or right ventricular assist device implanted; or
 - (bb) continuous infusion of intravenous inotropes.

For all adult patients listed as Status 1B, a completed Heart Status 1B Justification Form must be received by UNOS on UNetsm in order to list a patient_within one working day of a patient's listing as Status 1B. A patient who does not meet the criteria for Status 1B may nevertheless be assigned to such status upon application by his/her transplant physician(s) and justification to the applicable Regional Review Board that the patient is considered, using accepted medical criteria, to have an urgency and potential for benefit comparable to that of other patients in this status as defined above. The justification must include a rationale for incorporating the

exceptional case as part of the status criteria. A report of the decision of the Regional Review Board and the basis for it shall be forwarded to UNOS for review by the Thoracic Organ Transplantation and Membership and Professional Standards Committees to determine consistency in application among and within Regions and continued appropriateness of the patient status criteria.

- A patient who does not meet the criteria for Status 1A or 1B is listed as Status 2.
- A patient listed as Status 7 is considered temporarily unsuitable to receive a thoracic organ transplant.

Prior to downgrading any patients upon expiration of any limited term for any listing category, UNOS shall notify a responsible member of the relevant transplant team.

NOTE: Amendments to Policy 3.7.3 (Adult Patient Status) shall be implemented pending programming on the UNOS Computer System.

3.7.4 Pediatric Patient Status.

Each patient awaiting heart transplantation is assigned a status code which corresponds to how medically urgent it is that the patient receive a transplant. Medical urgency is assigned to a heart transplant patient who is less than 18 years of age at the time of listing as follows: Pediatric heart transplant patients who remain on the waiting list at the time of their 18th birthday without receiving a transplant, shall continue to qualify for medical urgency status based upon the criteria set forth in Policy 3.7.4.

Status Definition

- 1A A patient listed as Status 1A meets at least one of the following criteria:
- (a) Requires assistance with a ventilator;
- (b) Requires assistance with a mechanical assist device (e.g., ECMO);
- (c) Requires assistance with a balloon pump;
- (d) A patient less than six months old with congenital or acquired heart disease exhibiting reactive pulmonary hypertension at greater than 50% of systemic level. Such a patient may be treated with prostaglandin E (PGE) to maintain patency of the ductus arteriosus;
- (e) Requires infusion of high dose (e.g., dobutamine > 7.5 mcg/kg/min or milrinone > .50 mcg/kg/min) or multiple inotropes (e.g., addition of dopamine at > 5 mcg/kg/min); or
- (f) A patient who does not meet the criteria specified in (a), (b), (c), (d), or (e) may be listed as Status 1A if the patient has a life expectancy without a heart transplant of less than 14 days, such as due to refractory arrhythmia. Qualification for Status 1A under this criterion is valid for 14 days and may be recertified by an attending physician for one additional 14-day period. Any further extension of the Status 1A listing under this criterion_requires a conference with the applicable UNOS Regional Review Board.

Qualification for Status 1A under criteria (a) through (e) is valid for 14 days and must be recertified by an attending physician every 14 days from the date of the patient's initial listing as Status 1A to extend the Status 1A listing.

For all pediatric patients listed as Status 1A, a completed Heart Status 1A Justification Form must be received by UNOS on UNetsm in order to list a patient as Status 1A, or extend their listing as Status 1A in accordance with the criteria listed above in Policy 3.7.4. Patients who are listed as Status 1A

will automatically revert back to Status 1B after 14 days unless these patients are re-listed on UNetsm as Status 1A by an attending physician within the time frames described in the definitions of status 1A(a)-(e) above

- 1B A patient listed as Status 1B meets at least one of the following criteria:
- (a) Requires infusion of low dose single inotropes (e.g., dobutamine or dopamine < 7.5 mcg/kg/min);
- (b) Less than six months old and does not meet the criteria for Status 1A; or
- (c) Growth failure *i.e.*, + 5th percentile for weight and/or height, or loss of 1.5 standard deviations of expected growth (height or weight) based on the National Center for Health Statistics for pediatric growth curves.

Note: This criterion defines growth failure as either < 5th percentile for weight and/or height, or loss of 1.5 standard deviation score of expected growth (height or weight). The first measure looks at relative growth as of a single point in time. The second alternative accounts for cases in which a substantial loss in growth occurs between two points in time. Assessment of growth failure using the standard deviation score decrease can be derived by, first, measuring (or using a measure of) the patient's growth at two different times, second, calculating the patient's growth velocity between these times, and, third, using the growth velocity to calculate the standard deviation score (*i.e.*, (patient's growth rate - mean growth rate for age and sex) divided by standard deviation of growth rate for age and sex).

For all pediatric patients listed as Status 1B, a completed Heart Status 1B Justification Form must be received by UNOS on UNetsm in order to list a patient as Status 1B. A patient who does not meet the criteria for Status 1B may nevertheless be assigned to such status upon application by his/her transplant physician(s) and justification to the applicable Regional Review Board that the patient is considered, using accepted medical criteria, to have an urgency and potential for benefit comparable to that of other patients in this status as defined above. The justification must include a rationale for incorporating the exceptional case as part of the status criteria. A report of the decision of the Regional Review Board and the basis for it shall be forwarded to UNOS for review by the Thoracic Organ Transplantation and Membership and Professional Standards Committees to determine consistency in application among and within Regions and continued appropriateness of the patient status criteria.

- A patient who does not meet the criteria for Status 1A or 1B is listed as Status 2.
- A patient listed as Status 7 is considered temporarily unsuitable to receive a thoracic organ transplant.

Prior to downgrading any patients upon expiration of any limited term for any listing category, UNOS shall notify a responsible member of the relevant transplant team.

- **3.7.5** Allocation of Adolescent Donor Hearts to Pediatric Heart Candidates. Within each heart status, a heart retrieved from an adolescent organ donor shall be allocated to a pediatric heart candidate (i.e., less than 18 years old at the time of listing) before the heart is allocated to an adult candidate. For the purpose of Policy 3.7, an adolescent organ donor is defined as an individual who is 11 years of age or older, but less than 18 years of age.
- **3.7.6** <u>Status of Patients Awaiting Lung Transplantation</u> All patients awaiting isolated lung transplantation are considered to be the same urgency status for the purposes of thoracic organ allocation.
- **3.7.7** Allocation of Thoracic Organs to Heart-Lung Candidates. Candidates for a heart-lung transplant shall be registered on the individual UNOS Patient Waiting list for each organ. When

the patient is eligible to receive a heart in accordance with Policy 3.7, or an approved variance to this policy, the lung shall be allocated to the heart-lung candidate from the same donor. When the patient is eligible to receive a lung in accordance with Policy 3.7, or an approved variance to this policy, the heart shall be allocated to the heart-lung candidate from the same donor if no suitable Status 1A isolated heart candidates are eligible to receive the heart.

- **3.7.8 ABO** Typing for Heart Allocation. Within each heart status category, hearts will be allocated to patients according to the following ABO matching requirements:
- (i) Blood type O donor hearts shall only be allocated to blood type O or blood type B patients;
- (ii) Blood type A donor hearts shall only be allocated to blood type A or blood type AB patients;
- (iii) Blood type B donor hearts shall only be allocated to blood type B or blood type AB patients;
- (iv) Blood type AB donor hearts shall only be allocated to blood type AB patients.
- (v) If there is no patient available who meets these matching requirements, donor hearts shall be allocated first to patients who have a blood type that is compatible with the donor's blood type.

Following allocation for all transplant candidates who have blood types that are compatible with donors, hearts will be allocated locally first and then within zones in the sequence described in Policy 3.7.10, by heart status category to pediatric heart candidates less than one year of age who have a blood type that is incompatible with the donor's blood type if the candidate is listed with the blood type "Z" designation. Following allocation for incompatible pediatric heart candidates less than one year of age, hearts will be allocated, locally first and then within zones in the sequence described in Policy 3.7.10, to patients listed *in utero*.

3.7.8.1 Heart Allocation to Pediatric Candidates Registered Under Blood Type "Z."

For pediatric candidates who will accept a heart from a donor of any blood type, the blood type "Z" designation may be added as a suffix to the actual blood type (e.g., "AZ") of a pediatric candidate less than one year of age, or used alone if actual blood type is not known for *in utero* candidates.—

- **3.7.8.2 ABO Typing for Lung Allocation**. Patients who have the identical blood type as the donor and are awaiting an isolated lung transplant will be allocated thoracic organs before patients who have a compatible (but not identical) blood type with that of the donor and are awaiting an isolated lung transplant
- 3.7.9 Time Waiting for Thoracic Organ Candidates. Calculation of the time a patient has been waiting for a thoracic organ transplant begins with the date and time the patient is first registered as active on the UNOS Patient Waiting List. Waiting time will not be accrued by patients awaiting a thoracic organ transplant while they are registered on the UNOS Patient Waiting List as inactive. When time waiting is used for thoracic organ allocation, a patient will receive a preference over other patients who have accumulated less waiting time within the same status category. Waiting time accrued by a patient for a single thoracic organ transplant (heart or single lung) while waiting on the UNOS Patient Waiting List also may be accrued for a second thoracic organ, when it is determined that the patient requires a multiple thoracic organ (heart-lung or double lung) transplant. In addition, waiting time accrued by a patient for a multiple thoracic organ transplant while waiting on the UNOS Patient Waiting List may be transferred to the waiting list for a single thoracic organ transplant.
- 3.7.9.1 Waiting Time Accrual for Heart Candidates. Patients listed as a Status 1A, 1B, or 2 will accrue waiting time within each heart status; however, waiting time accrued while listed at a lower status will not be counted toward heart allocation if the patient is upgraded to a higher status. For example, a patient who is listed as a Status 2 for 3 months and then is upgraded to a Status 1A for one week will accrue one week of waiting time as a Status 1A. If the patient is downgraded to a Status 2 for another 3 weeks, then the patient will have 4 months of total

accrued time. If the patient subsequently is upgraded for another week as a Status 1A, then the patient's Status 1A waiting time will be 2 weeks.

- 3.7.9.2 Waiting Time Accrual for Lung Candidates with Idiopathic Pulmonary Fibrosis (IPF). A lung transplant candidate diagnosed with IPF shall be assigned 90 days of additional waiting time upon the candidate's registration on the UNOS Patient Waiting List.
- **3.7.10 Sequence of Heart Allocation.** Donor hearts shall be allocated in the following sequence in accordance with Policies 3.7.3, 3.7.4, 3.7.5, 3.7.7, 3.7.8, and 3.7.9:

Local

- 1. Status 1A patients
- 2. Status 1B patients
- 3. Status 2 patients

Zone A

- 4. Status 1A patients
- 5. Status 1B patients

Zone B

- 6. Status 1A patients
- 7. Status 1B patients

Zone A

8. Status 2 patients

Zone B

9. Status 2 patients

Zone C

- 10. Status 1A patients
- 11. Status 1B patients
- 12. Status 2 patients
- **3.7.11** <u>Allocation of Lungs.</u> Patients awaiting a lung transplant whether it is a single lung transplant or a double lung transplant will be grouped together for allocation purposes. If one lung is allocated to a patient needing a single lung transplant, the other lung will be then allocated to another patient waiting for a single lung transplant.
- Lungs will be allocated locally first, then to patients in Zone A, then to patients in Zone B, and finally to patients in Zone C. In each of those four geographic areas, patients will be grouped so that patients who have an ABO blood type that is identical to that of the donor are ranked according to time waiting; the lungs will be allocated in descending order to patients in that ABO identical type. If the lungs are not allocated to patients in that ABO identical type, they will be allocated in descending order according to time waiting to the remaining patients in that geographic area who have a blood type that is compatible (but not identical) with that of the donor. In summary, the allocation sequence for lungs is as follows:
- (i) First locally to ABO identical patients according to length of time waiting;
- (ii) Next, locally to ABO compatible patients according to length of time waiting;
- (iii) Next, to ABO identical patients in Zone A according to length of time waiting;
- (iv) Next, to ABO compatible patients in Zone A according to length of time waiting;
- (v) Next, to ABO identical patients in Zone B according to length of time waiting;
- (vi) Next, to ABO compatible patients in Zone B according to length of time waiting;
- (vii) Next, to ABO identical patients in Zone C according to length of time waiting; and
- (viii) Next, to ABO compatible patients in Zone C according to length of time waiting.

3.7.12 Minimum Information for Thoracic Organ Offers.

- **3.7.12.1** Essential Information. The Host OPO or donor center must provide the following donor information to the recipient center with each thoracic organ offer:
 - (i) The cause of brain death;
 - (ii) The details of any documented cardiac arrest or hypotensive episodes;
 - (iii) Vital signs including blood pressure, heart rate and temperature;
 - (iv) Cardiopulmonary, social, and drug activity histories;
 - (v) Serologies for HIV, hepatitis B and C, and CMV;
 - (vi) Accurate height, weight, age and sex;
 - (vii) ABO type;
 - (viii) Interpreted electrocardiogram and chest radiograph;
 - (ix) History of treatment in hospital including vasopressors and hydration;
 - (x) Arterial blood gas results and ventilator settings; and
 - (xi) Echocardiogram, if the donor hospital has the facilities.

The thoracic organ procurement team must have the opportunity to speak directly with responsible ICU personnel or the on-site donor coordinator in order to obtain current first-hand information about the donor physiology.

- **3.7.12.2** <u>Desirable Information for Heart Offers.</u> With each heart offer, the donor center is encouraged to provide the recipient center with the following information:
 - (i) Coronary angiography for male donors over the age of 40 and female donors over the age of 45;
 - (ii) CVP or Swan Ganz instrumentation;
 - (iii) Cardiology consult; and
 - (iv) Cardiac enzymes including CPK isoenzymes.
 - **3.7.12.3** Essential Information for Lung Offers. In addition to the essential information specified above for a thoracic organ offer, the Host OPO or donor center shall provide the following specific information with each lung offer:
 - (i) Arterial blood gases on 5 cm/ H_20 /PEEP including PO_2 /Fi O_2 ratio and preferably 100% Fi O_2 within 2 hours prior to the offer;
 - (ii) Measurement of chest circumference in inches or centimeters at the level of the nipples and x-ray measurement vertically from the apex of the chest to the apex of the diaphragm and transverse at the level of the diaphragm;
 - (iii) Chest radiograph interpreted by a radiologist or qualified physician within 3 hours prior to the offer;
 - (iv) Sputum gram stain with a description of the sputum character;
 - (v) Smoking history.
- **3.7.12.4** <u>Desirable Information for Lung Offers</u>. With each lung offer, the Host OPO or donor center is encouraged to provide the recipient center with the following information:
 - (i) Bronchoscopy results. Bronchoscopy of a lung donor is recognized as an important element of donor evaluation, and should be arranged at the discretion of the Host OPO or donor center. Confirmatory bronchoscopy may be performed by the lung retrieval team provided unreasonable delays are avoided. A lung transplant program may not insist upon performing its own bronchoscopy before being subject to the 60 minute response time limit as specified in Policy 3.4.1;
 - (ii) Mycology smear.
- **3.7.13** Status 1 Listing Verification. A transplant center which has demonstrated noncompliance with the Status 1 criteria specified in UNOS Policy 3.7.3 (Primary Allocation Criteria) for heart candidate registration shall be audited on a random basis and any recurrence of noncompliance will result in a recommendation to the Membership and Professional Standards Committee and

Executive Committee that further Status 1 heart candidate registrations from that center shall be subject to verification by UNOS of the candidates' medical status prior to their Status 1 placement on the UNOS waiting list for a period of one year.

- 3.7.14 Removal of Thoracic Organ Transplant Candidates from Thoracic Organ Waiting Lists When Transplanted or Deceased. If a heart, lung, or heart-lung transplant candidate on the UNOS Patient Waiting List has received a transplant from a cadaveric or living donor, or has died while awaiting a transplant, the listing center, or centers if the patient is multiple listed, shall immediately remove that patient from all thoracic organ waiting lists for that transplanted organ and shall notify UNOS within 24 hours of the event. If the thoracic organ recipient is again added to a thoracic organ waiting list, waiting time shall begin as of the date and time the patient is relisted.
- **3.7.15** <u>Local Conflicts Involving Thoracic Organ Allocation.</u> Regarding allocation of hearts, lungs and heart-lung combinations, locally unresolvable inequities or conflicts that arise from prevailing OPO policies may be submitted by any interested local member for review and adjudication to the UNOS Thoracic Organ Transplantation Committee and the UNOS Board of Directors.
- **3.7.16** Allocation of Domino Donor Hearts. A domino heart transplant occurs when the native heart of a combined heart-lung transplant recipient is procured and transplanted into a patient who requires an isolated heart transplant. First consideration for donor hearts procured for this purpose will be given to the patients of the participating transplant program from which the native heart was procured. If the program elects not to use the heart, then the heart will be allocated according to UNOS Policy 3.7, or an approved variance to this policy. For the purpose of Policy 3.7.16, the Local Unit of allocation for the domino heart shall be defined as the HCFA-designated service area of the OPO where the domino heart is procured.

Appendix 4: The Medical Act 1972

Short title.

1. This Act may be cited as the Medical (Therapy, Education and Research) Act.

Interpretation.

- 2. In this Act, unless the context otherwise requires —
- "deceased person" includes a still-born infant or foetus;
- "Director" means the Director of Medical Services, and includes the Deputy Director of Medical Services and the Superintendent of a Government hospital authorised by the Deputy Director of Medical Services in writing to act on his behalf;
- "donor" means an individual who makes a gift of all or any part of his body;
- "part", in relation to a human body, includes organs, tissues, eyes, bones, arteries, blood, other fluids and other portions of a human body.

Person may donate his body.

3. Any person of sound mind and 18 years of age or above may give all or any part of his body for any of the purposes specified in section 7, the gift to take effect upon death.

Relatives may donate body of deceased person.

- **4.** (1) Any of the persons specified in the Schedule, in the order of priority stated, when persons in prior classes are not available at the time of death, and in the absence of actual notice of contrary indications by the deceased person, or actual notice of opposition of a member of the same class or a prior class, may give all or any part of the body of the deceased person for the purposes specified in section 7.
- (2) The persons authorised by subsection (1) may make the gift after death or immediately before death.

When donee should not accept gift.

5. The donee of a gift of a body or any part thereof shall not accept the gift if he has actual notice of contrary indications by the deceased person or that a gift by a member of a class is opposed by a member of the same class or a prior class.

Medical examination of body.

6. A gift of all or any part of a body shall authorise any examination necessary to assure medical acceptability of the gift for the purposes intended.

Purposes of anatomical gifts, etc.

- **7.** (1) The following persons may become donees of gifts of bodies or parts thereof for the purposes stated:
- (a) any approved hospital for medical or dental education, research, advancement of medical or dental science, therapy or transplantation;
- (b) any approved medical or dental school, college or university for medical or dental education, research, advancement of medical or dental science, therapy or transplantation; or
- (c) any specified individual for therapy or transplantation needed by him.

(2) The Minister may, by notification in the *Gazette*, declare a hospital, medical or dental school, college or university to be an approved hospital, medical or dental school, college or university for the purposes of this section.

Mode of executing gift.

8. A gift of all or any part of a body under section 3 may be made by the donor either in writing at any time or orally in the presence of two or more witnesses during a last illness.

Revocation of gift.

- 9. A gift of a body or any part thereof may be revoked by the donor at any time —
- (a) by a signed statement in writing delivered to the donee;
- (b) by an oral statement made in the presence of two or more persons and communicated to the donee: or
- (c) by a written document to that effect found on his person or in his effects.

Donee need not be specified.

- **10.** (1) A gift of all or any part of the body of a deceased person may be made to a specified donee or without specifying a donee.
- (2) If the gift is made without specifying a donee, the Superintendent of the Government hospital in which the death of the deceased person has taken place or to which the body of the deceased person has been removed may accept the gift as donee upon or following the death for the purposes of section 7(1)(a) or (b), as the case may be.

Rights and duties of donee.

- **11.** (1) The donee may accept or reject the gift of a body or part thereof.
- (2) If the gift is of a part of the body of a deceased person, the donee shall cause the part to be removed without unnecessary mutilation. After removal of the part, custody of the remainder of the body shall vest in the surviving spouse, next of kin or other person under obligation to dispose of the body.

Authority to remove parts of unclaimed bodies.

12. Where the body of a deceased person has not been claimed from a hospital, nursing home or other institution, maintained on public funds, for more than 24 hours after death, the Director may authorise in writing the use of the body or any specified part for the purposes of medical or dental education, research, advancement of medical or dental science, therapy or transplantation.

Person may authorise post-mortem examination.

- **13.** (1) Any person of sound mind and 18 years of age or above may either in writing at any time or orally in the presence of two or more witnesses during his last illness authorise the post-mortem examination of his body for the purpose of establishing or confirming the cause of death or of investigating the existence or nature of abnormal conditions.
- (2) Such authority shall be effective upon the death of that person.

Relatives may authorise post-mortem examination.

14.—(1) Any of the persons specified in the Schedule, in the order of priority stated,

when persons in prior classes are not available at the time of death, and in the absence of actual notice of contrary indications by the deceased person, or actual notice of opposition of a member of the same class or a prior class, may authorise the post-mortem examination of the body of the deceased person for the purpose of establishing or confirming the cause of death or of investigating the existence or nature of abnormal conditions.

(2) The persons authorised by subsection (1) may give the authority after death or immediately before death.

Post-mortem examination of unclaimed body.

15. Where the body of a deceased person has not been claimed from a hospital, nursing home or other institution, maintained on public funds, for more than 24 hours after death, the Director may authorise in writing the post-mortem examination of the body for the purpose of establishing or confirming the cause of death or of investigating the existence or nature of abnormal conditions.

Removal and use of body to be lawful.

- **16.** (1) Subject to subsection (2), the removal and use of any part of a body in accordance with section 3 or 4, as the case may be, or the post-mortem examination of a body in accordance with the provisions of Part III, shall be lawful.
- (2) No such removal or post-mortem examination shall be effected except —
- (a) by a registered medical practitioner, who shall have satisfied himself that the death of the deceased person has been determined and certified in accordance with section 2A of the Interpretation Act (Cap. 1); or
- (b) with the written consent of the Coroner in a case where an inquiry is to be held in respect of the death of any person.

Power of Coroner unaffected.

17. Sections 3, 4, 13, 14 and 15 shall be without prejudice to the authority of the Coroner to direct the post-mortem examination of a body of a deceased person under the provisions of the Criminal Procedure Code. Cap. 68.

Appendix 5: The Human Organ Transplant Act (amended version)

<u>PART I</u> PRELIMINARY

Short title.

- **1.** This Act may be cited as the Human Organ Transplant Act. **Interpretation.**
- 2. In this Act, unless the context otherwise requires —
- "designated officer", in relation to a hospital, means a person appointed under section 4 to be the designated officer of the hospital;
- "Director" means the Director of Medical Services;
- "hospital" means —
- (a) a hospital established and administered by the Government;
- (b) a private hospital which is declared by the Minister by notification in the *Gazette*to be a hospital for the purposes of this Act;
- "medical practitioner" means a person who is registered, or deemed to be registered, as a medical practitioner under the Medical Registration Act; Cap. 174.

"organ" means —

- (a) except as provided in paragraph (b), the kidney of a human body; and
- (b) for the purposes of Part IV, any organ of a human body.

Designated officers.

4. The Director may nominate, in writing, any medical practitioner to be the designated officer of a hospital for the purposes of this Act.

PART II

REMOVAL OF ORGAN AFTER DEATH

Authorities may remove organ after death.

- **5.** (1) The designated officer of a hospital may, subject to and in accordance with this section, authorise, in writing, the removal of any organ from the body of a person who has died in the hospital for the purpose of the transplantation of the organ to the body of a living person.
- (2) No authority shall be given under subsection (1) for the removal of the organ from the body of any deceased person —
- (a) who has during his lifetime registered his objection with the Director to the removal of the organ from his body after his death;
- (b) unless his death was caused by accident or resulted from injuries caused by accident;
- (c) who is neither a citizen nor a permanent resident of Singapore;
- (d) who is below 21 years of age unless the parent or guardian has consented to such removal;
- (e) who is above 60 years of age;
- (f) whom the designated officer, after making such inquiries as are reasonable in the circumstances, has reason to believe was not of sound mind, unless the parent or guardian has consented to such removal; or
- (g) who is a Muslim.

- (3) Deleted by Act 22/98 wef 02/11/1998**
- (4) In this section, "permanent resident" includes —
- (a) a person who holds a Singapore blue identity card; and
- (b) a person who holds an Entry Permit or Re-entry Permit issued by the Controller of Immigration,

and who is not subject to any restriction as to his period of residence in Singapore imposed under the Immigration Act or any regulations made thereunder.

Coroner's consent.

- **6.** (1) If the designated officer of the hospital has reason to believe that the circumstances applicable to the death of the person are such that the Coroner has jurisdiction to hold an inquest into the manner and cause of death of the person, the designated officer shall not authorise the removal of any organ from the body of the deceased person unless the Coroner has given his consent to the removal.
- (2) The consent by the Coroner under this section may be expressed to be subject to such conditions as are specified in the consent.
- (3) The consent may be given orally by the Coroner, and if so given shall be confirmed in writing.
- (4) In this section, "Coroner" means a Coroner appointed under section 10 of the Subordinate Courts Act. Cap. 321.

Organ to be removed and transplanted by authorised medical practitioners.

- **7.** (1) No person other than an authorised medical practitioner in a hospital shall remove any organ which is authorised to be removed pursuant to section 5 or transplant any such organ.
- (2) For the purposes of subsection (1), "authorised medical practitioner" means a medical practitioner who has been authorised by the Director to remove any organ pursuant to section 5 or to transplant any such organ.
- (3) Any person who contravenes or fails to comply with subsection (1) shall be guilty of an offence and shall be liable on conviction to a fine not exceeding \$10,000 or to imprisonment for a term not exceeding one year or to both.

Operation of other laws.

8. Nothing in this Part shall prevent the removal of any organ from the bodies of deceased persons in accordance with the provisions of any other written law.

PART III
REGISTRATION OF OBJECTION
Persons may register their objection.

- **9.** (1) Any person who objects to the removal of any organ from his body after his death for the purpose mentioned in section 5 (1) may register his objection with the Director in the prescribed form.
- (2) Upon receipt of the written objection of a person under subsection (1), the Director shall issue to that person an acknowledgment in the prescribed form.

Director to maintain register.

- **10.** (1) The Director shall establish and maintain a register in which shall be entered the objection of all persons lodged in accordance with section 9.
- (2) The register referred to in subsection (1) shall not be open to inspection by the public.
- (3) Any person who wilfully destroys, mutilates or makes any unauthorised alteration in the register referred to in subsection (1) shall be guilty of an offence and shall be liable on conviction to a fine not exceeding \$10,000 or to imprisonment for a term not exceeding one year or to both.

Persons may withdraw their objection.

- **11.** (1) Any person who has registered his objection with the Director under section 9 may withdraw his objection in the prescribed form.
- (2) Upon receipt of the withdrawal under subsection (1), the Director shall issue to that person an acknowledgment in the prescribed form and shall remove the objection from the register referred to in section 10 (1).

Proposed recipients of organ.

- **12.** (1) Subject to subsection (2), in the selection of a proposed recipient of any organ removed pursuant to section 5 —
- (a) a person who has not registered any objection with the Director under section 9
- (1) shall have priority over a person who has registered such objection; and
- (b) a person who has registered his objection with the Director under section 9 (1) but who has withdrawn such objection under section 11 (1) shall have the same priority as a person who has not registered any such objection, over a person whose objection is still registered with the Director, at the expiration of two years from the date of receipt of the withdrawal by the Director provided he has not registered again any such objection since that date.
- (2) Notwithstanding subsection (1) (a) —
- (a) a person who is a Muslim shall have priority over a person who has registered such objection only if he has made a gift of his organ, to take effect upon his death, under section 3 of the Medical (Therapy, Education and Research) Act —
- (i) within 6 months from 16th July 1987;
- (ii) where that person is below 21 years of age, before or upon attaining the age of 21; or
- (iii) where that person is neither a citizen nor a permanent resident of Singapore within 6 months from the date he becomes a citizen or permanent resident of Singapore, whichever is earlier;

Cap. 175

- (b) a person who is a Muslim and has made a gift of his organ in accordance with paragraph (a) (i), (ii) or (iii) shall have the same priority as a person who has priority under subsection (1) (a) over a person whose objection is still registered with the Director, with effect from the date of such gift provided that such priority shall cease immediately upon the revocation of such gift; and
- (c) a person who is a Muslim and has made a gift of his organ under the Medical (Therapy, Education and Research) Act after the period prescribed in paragraph (a) (i), (ii) or (iii) shall have the same priority as a person who has priority under subsection (1) (a) over a person whose objection is still registered with the Director, at the expiration of two years from the date of such gift provided he has not revoked his gift since that date.

 Cap. 175.

Appointment of a committee.

13. The Director may appoint a committee consisting of not less than 5 members to be in charge of matters relating to the selection of proposed recipients of any organ removed pursuant to section 5 and such other matters as may be directed by the Director from time to time

PART IV

PROHIBITION OF TRADING IN ORGANS AND BLOOD

Certain contracts etc., to be void.

- **14.** (1) Subject to this section, a contract or arrangement under which a person agrees, for valuable consideration, whether given or to be given to himself or to another person, to the sale or supply of any organ or blood from his body or from the body of another person, whether before or after his death or the death of the other person, as the case may be, shall be void.
- (2) A person who enters into a contract or arrangement of the kind referred to in subsection (1) and to which that subsection applies shall be guilty of an offence and shall be liable on conviction to a fine not exceeding \$10,000 or to imprisonment for a term not exceeding one year or to both.
- (3) Subsection (1) shall not apply to or in relation to —
- (a) a contract or arrangement providing only for the reimbursement of any expenses necessarily incurred by a person in relation to the removal of any organ or blood in accordance with the provisions of any other written law; and
- (b) any scheme introduced or approved by the Government granting medical benefits or privileges to any organ or blood donor and any member of the donor's family or any person nominated by the donor.
- (4) The Minister may, by notification in the *Gazette*, declare that subsection (1) shall not apply to the sale or supply of a specified class or classes of product derived from any organ or blood that has been subjected to processing or treatment.
- (5) A person who as vendor or supplier enters into a contract or arrangement for the sale or supply of a product derived from any organ or blood that has been subjected to processing or treatment, other than such a product which is of a class declared under subsection (4), shall be guilty of an offence if the organ or blood from which the product was derived was obtained under a contract or arrangement that is void by reason of subsection (1) and shall be liable on conviction to a fine not exceeding \$10,000 or to imprisonment for a term not exceeding one year or to both.

(6) Nothing in this section shall render inoperative a consent or authority given or purporting to have been given under this Act in relation to any organ or blood from the body of a person or in relation to the body of a person if a person acting in pursuance of the consent or authority did not know and had no reason to know that the organ or blood or the body was the subject-matter of a contract or arrangement referred to in subsection (1).

Advertisements relating to buying or selling of organs or blood prohibited.

- **15.** (1) No person shall issue or cause to be issued any advertisement relating to the buying or selling in Singapore of any organ or blood or of the right to take any organ or blood from the body of a person.
- (2) In this section, "advertisement" includes every form of advertising, whether in a publication, or by the display of any notice or signboard, or by means of any catalogue, price list, letter (whether circular or addressed to a particular person) or other documents, or by words inscribed on any article, or by the exhibition of a photograph or a cinematograph film, or by way of sound recording, sound broadcasting or television, or in any other way, and any reference to the issue of an advertisement shall be construed accordingly.
- (3) Any person who contravenes or fails to comply with subsection (1) shall be guilty of an offence and shall be liable on conviction to a fine not exceeding \$10,000 or to imprisonment for a term not exceeding one year or to both.

PART V

MISCELLANEOUS

Act does not prevent specified removal of organ, etc.

- **16.** (1) Nothing in this Act shall apply to or in relation to —
- (a) the removal of any organ from the body of a living person in the course of a procedure or operation carried out, in the interests of the health of the person, by a medical practitioner with the consent, express or implied, given by or on behalf of the person or in circumstances necessary for the preservation of the life of the person;
- (b) the use of any organ so removed;
- (c) the embalming of the body of a deceased person; or
- (d) the preparation, including the restoration of any disfigurement or mutilation, of the body of a deceased person for the purpose of interment or cremation.

Offences in relation to removal of organ.

- **17.** (1) No person shall remove any organ from the body of a deceased person for the purpose referred to in section 5 (1) except in pursuance of the authority given under Part II.
- (2) Any person who contravenes or fails to comply with subsection (1) shall be guilty of an offence and shall be liable on conviction to a fine not exceeding \$10,000 or to imprisonment for a term not exceeding one year or to both.

Disclosure of information.

- **18.** (1) Subject to this section, a person shall not disclose or give to any other person any information or document whereby the identity of a person —
- (a) from whose body any organ has been removed for the purpose of transplantation;
- (b) with respect to whom or with respect to whose body a consent or authority has been given under this Act; or
- (c) into whose body any organ has been, is being, or may be, transplanted, may become publicly known.
- (2) Subsection (1) shall not apply to or in relation to any information disclosed —
- (a) in pursuance of an order of a Court or when otherwise required by law;
- (b) for the purposes of hospital administration or bona fide medical research;
- (c) with the consent of the person to whom the information relates; or
- (d) when the circumstances in which the disclosure is made are such that the disclosure is or would be privileged.
- (3) Any person who contravenes or fails to comply with subsection (1) shall be guilty of an offence and shall be liable on conviction to a fine not exceeding \$10,000 or to imprisonment for a term not exceeding one year or to both.

Regulations.

- **19.** The Minister may make regulations prescribing all matters that are required or permitted to be prescribed by this Act or are necessary or convenient to be prescribed for carrying out or giving effect to this Act.
- ** The deleted section in original bill as drawn out in 1986:
- (3) The death of a person from whose body the organ will be removed after his death in accordance with the authorization granted under subsection (1) shall be certified by two medical practitioners –
- (a) Who do not belong to the team of medical practitioners which will effect the removal of the organ from the body.
- (b) Who have not been involved in the care and treatment of the proposed recipient of the organ

Who possess such postgraduate medical qualifications which is recognized by the Director as a qualification entitling them to certify the death of a person under this subsection.

Appendix 6: The Interpretation Bill: Criteria for determining death

- **2A.**—(1) For all purposes, a person has died when there has occurred either (a) irreversible cessation of circulation of blood and respiration in the body of the person; or
- (b) total and irreversible cessation of all functions of the brain of the person.

[22/98]

(2) The determination of the irreversible cessation of circulation of blood and respiration in the body of a person shall, subject to subsection (4), be made in accordance with the ordinary standards of current medical practice; and the determination of the total and irreversible cessation of all functions of the brain of a person shall, subject to subsections (3) and (5), be made in accordance with the prescribed criteria.

[22/98]

- (3) Except in the circumstances referred to in subsection (5), the determination of the total and irreversible cessation of all functions of the brain of a person shall be certified in the prescribed form by 2 medical practitioners —
- (a) at least one of whom has not been involved in the care or treatment of the person so certified; and
- (b) who possess the prescribed postgraduate medical qualifications.

[22/98]

(4) If the death of a person from whose body an organ is to be removed after his death as authorised under the Human Organ Transplant Act (Cap. 131A) or the Medical (Therapy, Education and Research) Act (Cap. 175) is determined by the irreversible cessation of circulation of blood and respiration in the body of that person, his death shall be certified in the prescribed form by 2 medical practitioners

(a) who have not been involved in the care or treatment of the person so certified;

- (b) who do not belong to the team of medical practitioners which will effect the removal of the organ from the body;
- (c) who have not been involved in the selection of the proposed recipient of the organ; and
- (d) who will not be involved in the care or treatment of the proposed recipient of the organ during his hospitalisation for the purpose of the transplant.

[22/98]

- (5) If the death of a person from whose body an organ is to be removed after his death as authorised under the Human Organ Transplant Act (Cap. 131A) or the Medical (Therapy, Education and Research) Act (Cap. 175) is determined by the total and irreversible cessation of all functions of the brain of that person, his death shall be certified in the prescribed form by 2 medical practitioners —
- (a) who have not been involved in the care or treatment of the person so certified;
- (b) who do not belong to the team of medical practitioners which will effect the removal of the organ from the body;
- (c) who have not been involved in the selection of the proposed recipient of the organ;
- (d) who will not be involved in the care or treatment of the proposed recipient of the organ during his hospitalisation for the purpose of the transplant; and
- (e) who possess the prescribed postgraduate medical qualifications.

[22/98]

- (6) The Minister may, for the purposes of all laws or any specified written law, by regulations prescribe —
- (a) the criteria for determining the total and irreversible cessation of all functions of the brain of a person referred to in subsections (1) (b) and (2); and
- (b) the postgraduate medical qualifications and form of the death certificate for the purposes of subsection (3), (4) or (5).

[22/98]

- (7) Nothing in this section shall —
- (a) affect the operation of section 110 of the Evidence Act (Cap. 97) (burden of proving that a person is alive who has not been heard of for 7 years), section 100 of the Women's Charter (Cap. 353) (proceedings for decree nisi of presumption of death and divorce) or any other written law relating to the presumption of death; (b) prevent the certification or determination of death in a case where the body of a person is not found or recovered.

[22/98]

(8) In this section, "medical practitioner" means a person who is registered, or deemed to be registered, as a medical practitioner under the Medical Registration Act (Cap. 174).

[22/98]

Bibliography

Aaron, H.J., & Schwartz, W.B.

1984 The painful prescription: Rationing hospital care.

Washington, D.C.: Brookings Institution.

Berlyn, G.M.

"Over 50 and Uremic = Death". *Nephron* 39.

CancerWeb

2002 On-line Medical Dictionary. Dept. of Medical Oncology, University

f Newcastle upon Tyne.

http://cancerweb.ncl.ac.uk/cgi-bin/omd?query=triage

2002 On-line Medical Dictionary. Dept. of Medical Oncology, University of Newcastle upon Tyne

http://cancerweb.ncl.ac.uk/cgi-bin/omd?transplantation,+autologous

Caplan, A.L.

"Equity in the selection of recipients for cardiac transplantation".

Circulation vol. 75.

Carter-Jones, L

1983 "Politics, Mortality and Economics – Are there Choices?" in F.M.

Parsons and C.S. Ogg, Renal Failure - Who Cares? Lancaster

England.

Childress, J.F.

"Who shall live when not all can live". *Soundings* vol. 53.

Chua, Beng Huat

1995 "Ideological Trajectory: from Authoritarianism to

Communitarianism". Communitarian Ideology and Democracy in

Singapore. London; New York: Routledge

Cimato, Thomas L; Jessup, Mariell

2002 "Recipient selection in cardiac transplantation: contraindications and

risk factors for mortality". The Journal of Heart and Lung

Transplantation vol. 21, issue 11. pp. 1161-1173

Clammer, John.

"Deconstructing values: the establishment of a National Ideology and

its implications for Singapore's political future". Singapore Changes Guard: Social, Political and Economic Directions in the 1990s. Ed.

Garry Rodan. New York: St. Martin's Press

Cohen, C.; Benjamin, M.

1991 "Alcoholic

"Alcoholics and Liver Transplantation". *Journal of the American Medical Association* vol. 265. pp. 1299-1301

Davidson, Robert C. and Scribner, Belding H.

1967

"Patient Selection for Maintenance Dialysis". In R.C. Davidson and B.H. Scribner, *A Physician's Syllabus for the Treatment of Chronic Uremia*. Seattle: University of Washington and Seattle Artificial Kidney Center.

D'Alessandro AM.; Sollinger HW.; Knechtle S, et al.

"Living related unrelated donors for kidney transplantation: a 28-year

experience. Ann Surg vol 222. pp. 353-364

Debakey, Michael E., and Lois Debakey

1983 "The Ethics and Economics of High-Technology Medicine"

Comprehensive Therapy 9.

Devries, William C. et al

"Clinical Use of the Total Artificial Heart" New England Journal of

Medicine 310.

Elster, Jon

1992 Local Justice: how institutions allocate scarce goods and necessary

burdens. Cambridge: Cambridge University Press

Evans, Roger W., and Diane L.Manninen.

1987

"Public Opinion Concerning Organ Donation, Procurement, and Distribution." Results of a survey conducted for UNOS by Battelle Human Affairs Research Centers, Seattle, WA. Partially Published in *Transplantation Proceedings* 20 (Oct 1998): 781-85

Ferguson RM.

1988

"Treatment Protocols: is there a role for tissue typing in renal transplantation? *Transplant Procedure* vol. 6. pp. 42-45

Forensius Medical Care

2002

The Function of the Kidneys. Forensius Medical Care http://www.fmcag.com/internet/fmc/fmcag/agintpub.nsf/Content/The+Function+of+Kidneys

Fox, Renee C. and Swazey, Judith P.

1974 The Courage to Fail: a social view of organ transplants and dialysis. Chicago: University of Chicago Press

Chicago: University of Chicago Press

1992 Spare Parts: organ replacement in American Society. New York. Oxford University Press

Friedrich, Otto

"One Miracle, Many Doubts". *Time* 124.

Glannon, W.

"Responsibility, Alcoholism, and Liver Transplantation". *Journal of*

Medicine and Philosophy vol 23. pp. 31-49

Gow, P.J.; Pillay, D.; Mutimer, D.

2001 "Solid Organ Transplantation in Patients with HIV Infection".

Transplantation vol. 72. pp. 177-178

Halpern, S.; Ubel, P.A.; Caplan, A.L.

2002 "Solid Organ Transplantation in HIV-infected Patients". The New

England Journal of Medicine vol. 347. pp. 284-287

HealthSquare

2002 Dealing with Liver Disease. HealthSquare

http://www.healthsquare.com/fgpd/fg4ch20.htm

Hendee, William, R.

1986 "Rationing Health Care" in James Hamner III and Barbara Jacobs.

Life and Dearth Issues. Memphis: University of Tenessee Press.

Inglehart, R.

"Changing values, economic development and political change".

International Social Science Journal 145

iKidney.com

2002 Antigens and Antibodies - The Foreign Language of Transplantation.

iKidney.com

http://www.ikidney.com/iKidney/Community/Pro2Pro/Nurses/Antige

nsandAntibodies.htm

Jackson, David L. and George J. Annas

"The Introduction of Major Organ Transplantation on the State Level:

Ethical and Practical Considerations in the Development of Public Policy" in Stuart Youngner, *Human Values in Critical Care Medicine*.

New York: Praeger: 109-22.

Jonsen, Albert R., et al

1982 *Clinical Ethics*. New York: Macmillian.

Kidney Dialysis Foundation, Singapore

2002 Patient's Selection and Subsidies. Kidney Dialysis Foundation,

Singapore http://www.kdf.org.sg/subsidy.htm

Kilner, John Frederic

1990 Who Lives? Who Dies?: Ethical criteria in patient selection. New

Haven: Yale University Press

Kimball, J.W.

2002 Organ Transplants. Kimball, J.W.

http://users.rcn.com/jkimball.ma.ultranet/BiologyPages/T/Transplants.

<u>html</u>

Kliemt, H.

2003 "Club and Reciprocity in Organ Transplantation". Paper prepared for the meeting of Japan Economic Policy Association (JEPA)

Kuo, P.C.

2001 "Reconsideration of HIV as a Contraindication to Transplantation".

Transplantation vol. 71. pp. 1689

Lamping, Donna L. et al

"Clinical outcomes, quality of life, and costs in the North Thames

Dialysis Study of elderly people on dialysis: a prospective cohort

study" The Lancet vol. 356. pp. 1543-1550

Lawnet

2002a Human Organ Transplant Act, Chapter 131A. Singapore Academy of

Law, Singapore http://statutes.agc.gov.sg/

2002b Medical (therapy, education and research) Act, Chapter 175.

Singapore Academy of Law, Singapore http://statutes.agc.gov.sg/

2002c The Interpretation Act, Criteria for determining death, Chapter 1.

Singapore Academy of Law, Singapore http://statutes.agc.gov.sg/

Lefebvre, Diane

"Allocation of Scarce Medical Resources". Science and Ethical

Responsibility. Reading M.A.: Addison-Wesley.

Lock, Margaret

Twice Dead: Organ Transplant and the Reinvention of Death.

Berkeley, University of California Press.

Matthieu, D.

"Introduction to Part 2" In D. Matthieu, Organ Substitution

Technology. Boulder, CO: Westview Press.

Mauss, Marcel

1967 The Gift; forms and functions of exchange in Archaic Societies. Trans. by Ian Cunnison. New York, Norton

162

Meissner, Joseph 1986 "Legal Services and Medical Treatment for Poor People: A Need for Advocacy" Issues in Law and Medicine 2. Meyers, David W. 1977 "California Natural Death Act: A Critical Appraisal". California State Bar Journal 52. Ministry of Health, Singapore 2002a Health Facts Singapore 2002. Ministry of Health, Singapore http://app.moh.gov.sg/sta/sta0102.asp 2003 Proposed Amendments To The Human Organ Transplant Act. Ministry of Health National Kidney Foundation, Singapore 2002a Kidney Failure. National Kidney Foundation, Singapore http://www.nkfs.org/kidney resource centre/kidney failure/causes.ht ml 2002b Centres. National Kidney Foundation, Singapore Our http://www.nkfs.org/visitor centre/tour our centres/dialysis centre t our.html 2002c Prevention. National Kidney Foundation, Singapore http://www.nkfs.org/kidney_resource_centre/prevention/hypertension. html 2002d Timeline. Singapore National Kidney Foundation, http://www.nkfs.org/visitor_centre/timeline/founding.html 2002e

2002e Criteria for kidney transplant. National Kidney Foundation, Singapore http://www.nkfs.org/kidney_resource_centre/transplant/criteria.html

Neff, Guy W.; Jayaweera Dushyantha; Tzakis, Andrea G.

2002 "Liver transplantation for HIV-infected patients with end-stage liver disease." Current Opinion in Organ Transplantation vol. 7. pp. 114-123

Neuberger, James; James, Oliver

"Guidelines for selection of patients for liver transplantation in the era of donor-organ shortage". The Lancet vol 354. pp. 1636-1639

"Patient Selection for Artificial and Transplanted Organs"

1969 Harvard Law Review 1982.

Parsons, Victor, and P.M. Lock

"Triage and the Patient with Renal Failure" *Journal of Medical Ethics*

6.

Pearlman, Robert, A. et al

"Variability in Physician Bioethical Decision-Making: A Case Study

of Euthanasia" Annuls of Internal Medicine 97.

Prachalias, A.; Pozniak, A.; Taylor, Ch, et al.

2001 "Liver Transplantation in Adults Coinfected with HIV".

Transplantation vol. 72. pp. 1684-1688

Quah, Stella

1981 "Health Policy and Traditional Medicine in Singapore". Social

Science and Medicine. 15A.

"The Best Bargain: Medical Option in Singapore". The Triumph of

Practicality. Institute of Southeast Asian Studies.

Ramsey, Paul

"Choosing How to Choose: Patients and Sparse Medical Resources".

The Patient as Person. New Haven, Yale University Press.

Rescher, N.

"The Allocation of Exotic Medical Lifesaving Therapy". *Ethics* vol.

79.

Robertson, John A.

"Supply and Distribution of Hearts for Transplantation: Legal, Ethical

and Policy Issues" Circulation 75.

Rodan, Garry

"Class Transformation and Political Tensions in Singapore's

development". The New rich in Asia: mobile phones, McDonalds and middle-class revolution. Ed. by Richard Robison and David S.G.

Goodman. London; New York: Routledge

Rothman, S.A., & D.J. Rothman

2003 "The organ market." New York Review of Books

Scarce Medical Resources

1969 Columbia Law Review 9

Schmidt, Volker

"Selection of Recipients for Donor Organs in Transplant Medicine".

The Journal of Medicine and Philosophy. Vol. 23, No. 1, pp. 50-74.

Swets and Zeitlinger

1998a "Politics of Justice and the Paradox of Justification". Social Justice

Research 11.

2002 "Technicization of Institutional Practice and the Invisibilization of the Social". Unpublished Manuscript.

Schmidt Volker H and Chee-Han Lim.

2004 "Organ transplantation in Singapore: History, problems, and

policies". Social Science & Medicine.

Schweizer, R.T., Rovelli, M., Palmeri, D., Vossler, E., Hull, D., & Bartus, S.

"Noncompliance in organ transplant recipients". *Transplantation 49*

Simmons, Roberta G and Simmons, Richard L.

"Sociological and Psychological Aspects of Transplantation" In J.S. Najarian and R.L. Simmons. *Transplantation*. Philadelphia: Lea and

Febiger.

Singapore National Heart Association

2002 Heart Matters. Singapore National Heart Association

http://www.snha.org/heart matters/dnc heart failure.htm

Stock P.; Roland, M.; Carlson, L. et al.

2001 "Solid Organ Transplantation in HIV positive Patients".

Transplantation Proceedings vol. 33. pp. 3646-3648

Sutherland, Matas AJ; Najarian JS

"The impact of HLA matching on graft survival". Transplantation

vol.54. pp. 568-569

United Nations, Secretary General

"Human Rights and Scientific and Technological Developments". 30th

Session, Item 70 of the Provisional Agenda.

Task Force on Organ Transplantation

1986 Organ Transplantation: Issues and Recommendations. Rockville,

MD: US. Department of Health and Human Services

The Gift

2002 Critical Statistics. Multi Organ Donation Development, Singapore.

http://www.thegift.org.sg/why organ donation/critical statistics.html

The Straits Times, Singapore.

Singapore Press Holdings

Thompson, Mark E.

"Selection of Candidates for Cardiac Transplantation" Heart

Transplantation 3.

Terasaki PI.; Cecka JM.; Gjertson DW.; Tekemoto S.

"High survival rates of kidney transplants from spousal and living unrelated donors". *New England Journal of Medicine* vol. 333. pp.

333-336.

TransWeb.Org.

2002 Frequently asked questions about Xenotransplants. TransWeb.Org

http://www.transweb.org/qa/qa_txp/faq_xeno.html

United Network for Organ Sharing

1989 "UNOS Policy Regarding Utilization of the Point System for

Cadaveric Kidney Allocation". Richmond, Virginia.

2003a "Questions and Answers for Patients and Families about MELD and

PELD".UNOS.

http://www.unos.org/waitlist/includes local/pdfs/meld 20020213 Pat

ient.pdf

2003b "MELD/PELD calculator: Information for Patients/FAQ". UNOS.

http://www.transplantliving.org/waitlist/includes local/pdfs/meld.pdf

Walzer, Michael

1983 Spheres of Justice: a defence of pluralism and equality. Oxford:

Martin Robertson

WebHealthCentre.com

2002 Renal Failure. WebHealthCentre.com

http://www.webhealthcentre.com/centers/kidney.asp

Young, Robert

1975 "Some Criteria for Making Decisions Concerning the Distribution of

Scarce Medical Resources". Theory and Decision 6.