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UNIVERSITY OF SOUTHAMPTON

FACULTY OF BUSINESS AND LAW

School of Law

**A SOCIO-LEGAL STUDY ON ORGAN SHORTAGE
IN MALAYSIA**

by

FARAH SALWANI MUDA@ISMAIL

Thesis for the degree of Doctor of Philosophy

May 2012

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF BUSINESS AND LAW

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A SOCIO LEGAL STUDY ON ORGAN SHORTAGE IN MALAYSIA

by Farah Salwani Muda @ Ismail

Human organs are the most valuable gifts of life. Until today, through organ transplantation, thousands of lives have been saved and many more blessed with hope and happiness through a better quality of living. However, rapid developments in transplant technology will be meaningless if supply of the needed organs remains scarce and organ transplantation procedures cannot take place accordingly. This global problem of organ shortage is also faced by Malaysia. Despite campaigns and initiatives introduced by the Malaysian authorities, the problem remains unresolved and the situation is worsening. Malaysia is reported to have less than one donor for every one thousand of the population (Lela Yasmin Mansor, 2007). However, statistics from the National Transplant Registry Malaysia confirm a steady increase in the number of registered potential donors each year. This suggests that certain factors must be preventing potential donors from becoming actual donors. Therefore, this study will not only discuss the current scenario of the organ shortage problem in Malaysia, highlighting its underlying factors, but will also scrutinise legal and social factors causing actual donations to remain relatively small, despite the promising number of potential donors registering each year. The study will suggest practical solutions to help solve organ shortages in Malaysia, particularly by utilising brain-dead patients from serious road traffic accidents as a potential source of cadaveric organs. Clarification on the Islamic perspective concerning organ donation is also included, as Islam is the main religion professed in Malaysia.

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IRAN

Organ Transplantation Act 2000

KUWAIT

Islamic Code of Medical Ethics. Kuwait. January 1981

MALAYSIA

Age of Majority Act 1971

Federal Constitution of Malaysia

Human Tissues Act 1974

Road Traffic Act 1987 (Act 333)

SINGAPORE

Human Organ Transplants Act 1987, act 15 of 1987

Medical (Therapy, Education and Research) Act (MTERA) 1973

THE UNITED KINGDOM

Human Tissue Act 1961

Human Organ Transplants Act 1989

Human Tissue Act 2004

Mental Capacity Act 2005

Human Tissue Authority Code of Practice-Consent. Code 1 July 2006

The Anatomy Act 1961

The Anatomy Act 1984

The Corneal Tissue Act 1987

THE UNITED STATES

National Transplantation Act 1984

Organ Donation and Recovery Improvement Act (ODRIA), 42 U.S.C.274f

Uniform Determination of Death Act 1980

ABBREVIATIONS

Am.J.Transplant	American Journal of Transplantation
Ann Acad Med Singapore	Annals Academy of Medicine Singapore
Ann Transplant	Annals of Transplantation
Arch Dis Child	Archives of Disease in Childhood
BMJ	British Medical Journal
Can Med Assoc	Canadian Medical Association Journal
Clin J Am Soc Nephrol	Clinical Journal of the American Society of Nephrology
Clin Res	Clinical Resources
<i>CMAJ</i>	<i>Canadian Medical Association Journal</i>
<i>Crti Care Nurse</i>	<i>Critical Care Nurse</i>
DePaul L.Rev	DePaul Law Review
HEC Forum	HealthCare Ethics Committee Forum
HOTA	Human Organ Transplant Act
Ital J Neurol Sci	Italian <i>Journal</i> of Neurological Sciences
<i>J Health Psychol</i>	<i>Journal of Health Psychology</i>
J Kid Dis Transplant	Saudi Journal of <i>Kidney</i> Diseases and Transplantation
J Med Ethics	Journal of Medical Ethics
<i>J Transplant Coordination</i>	<i>Journal of Transplant Coordination</i>
<i>J Urol</i>	<i>The Journal of Urology</i>
JAMA	The Journal of the American Medical Association

Med Law Review	Medical Law Review
Med Law	Medicine and Law
MUIS	Majlis Ugama Islam Singapore (Head of Religious Council Singapore)
N Eng J Med	The New England Journal of Medicine
Nat Clin Pract Nephrol	Nature Clinical Practice Nephrology
Nephrol Dial Transplant	Nephrology Dialysis Transplantation
No.	Number
NTR	National Transplant Registry
Para	Paragraph
Pediatr Nephrol	Pediatric Nephrology
Postgrad Med J	Postgraduate Medical Journal
St.Mary's L.J	St Mary's Law Journal
Transplant Int	Transplant International
UTAC	Unrelated Transplant Approval Committee
Va J Soc Pol'y & L	Virginia Journal of Social Policy and the Law
Vol	Volume
WHO	World Health Organization
World J Surg	World Journal of Surgery

DECLARATION OF AUTHORSHIP

I, Farah Salwani Muda @ Ismail, declare that the thesis entitled “A socio legal study on organ shortage” and the work presented in the thesis are both my own, and have been generated by me as the result of my own originals research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- Where I have consulted the published work of others, this is always clearly attributed;
- Where I have quoted from the work of others, the sources is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- None of this work has been published before submission.

Signed:

Dated : 10 May 2012

ACKNOWLEDGEMENTS

Firstly, I would like to express my profound thanks to my respected supervisor, Dr Remigius Nwabueze, for his valuable advices and guidance given to me, throughout the writing of this thesis. His support gave me courage and confidence to complete the thesis. I would also like to thank Professor Jonathan Montgomery, my advisor and Dr Caroline Jones, who were the panel in my upgrading procedures, both gave me valuable comments on my work. My thanks also to the late Professor David Price and Professor Hazel Biggs, the panel for my viva examinations, who made my viva a wonderful, unforgettable experience.

I would also like to address my gratitude to Dr. Marina, Dr. Ghazali, Dr Zahari, Dato' Abdul Syukur and Pn Jamaliah Kario for their willingness to contribute to my research through interviews conducted with them. And also to the Government of Malaysia for sponsoring my studies.

My stay in Southampton, UK would not have been possible without the presence of my beloved husband, Dr. Muhamad bin Ismail, who sacrificed a lot, for the sake of my studies. No words can describe my gratitude for his continuous support, comfort and love that showered me. Also to my children, Muhammmad Fahmi Hakim, Nur Najiha Husna, Muhammad Faiz Aiman and Nur Aleesya Madhiha, I cherish all the joyful moments and laughter that you bring, that always cheered up my stressful moments.

I am also grateful to my late father, Professor Muda @Ismail Ab Rahman who will always be my inspiration and strength. To my beloved mother, Zainab binti Hashim, your support and understanding has always kept me strong to face all the challenges ahead. Both have loved and taken good care of me since the day I was born. Their love will remain in my heart forever. To my brothers and sisters, Farah Laili, Muhammad Iqbal, Muhammad Zaiyad, Muhammad Irfan, Muhammad Haikal, Farah Wardati and Farah Hanani, I hope that you will all succeed in your future and thank you, for all your good wishes.

Finally, I would also like to express my gratitude to all the School of Law staffs, particularly Mrs.Gill Sivyour, Mrs. Karen Constable and Mrs.Aloma Hacks for all their help in making my studies at Southampton University an enjoyable experience. My sweet memories at the Southampton University will be treasured in my heart throughout my life.

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A SOCIO-LEGAL STUDY ON ORGAN SHORTAGE IN MALAYSIA

INTRODUCTION

Organ donation is one of the miracles of modern medical science, and is the best life-saving therapy for patients with end-stage failure of most essential organs. However, even though this technology has managed to bring hope to many dying and chronically diseased patients and has saved thousands of valuable lives, organ shortage is becoming a huge barrier preventing many more people from benefitting. The demand for human organs is growing ever higher; supply, in contrast, is very limited, causing preventable deaths and suffering among chronically-ill patients. Waiting lists are extensive, causing the average period of waiting for an organ to increase dramatically. This problem of organ shortage which started to emerge in the mid-1980s¹ is also contributing towards the lost of potential human resources as many more patients die while waiting for the needed organs.

Malaysia also faces organ shortage problems although, in general, Malaysians *do* accept the practice of organ donation. As a developing country of approximately 28 million people, Malaysia unfortunately has less than one donor for every one million population². Statistics from the National Transplant Registry of Malaysia show that, from 1997 until May 2009, an inspiring number of 128,556 persons registered voluntarily as potential donors; however, only 229 cadaver donations have actually taken place since 1976³. So, there must be certain reasons why these potential registered donors are prevented from becoming actual donors, which indirectly causes the organ shortage problems. Therefore, this thesis will try to identify those factors that are preventing registered potential donors from becoming actual donors. The thesis will propose necessary and effective steps that should be taken by Malaysia to ensure an increase in the number of actual donors and

¹ Martine Rothblatt, *Your Life or Mine*, (England , Ashgate Publishing Limited, 2004) p. 2.

² A donation rate of 0.99 per million of population (pmp) was reported in the *Fourth Report of the National Transplant Registry 2007*, (Kuala Lumpur, National Transplant Registry, 2007), p.170.

³ <http://www.agifttolife.gov.my>

subsequently allow more potential organs to be available for the benefit of those patients in desperate need of them.

A socio-legal approach is taken to tackle this organ shortage issue, as social and legal factors are closely related to each other. In order to suggest the best applicable solution, it is essential to first understand the specific dynamics of Malaysia, which comprises a mixed population, practising various religions and customs. It is important to understand the underlying social factors contributing towards the issue, before any specific socio-legal remedy can be suggested. Additionally, although the approach taken will not necessarily produce a new law or system to be applied, it will at least enhance the application and governance of any alternative solutions proposed, which include improving the application of the existing opting-in organ donation system, promoting family members to become witnesses in the registration of organ donor procedure and reducing family powers to withdraw the consent made by their family members to donate organs. Administrative reforms, such as taking organs from road traffic accident victims, providing incentives for every organ donated and having an efficient database that could efficiently identify registered organ donors, also seem necessary.

The thesis will also highlight details and findings obtained from an empirical study conducted in the Klang Valley and the district of Hulu Langat, Malaysia, conducted between December 2007 and February 2008. The Klang Valley location was chosen because most of the people residing there are from different parts of the country. There are a few public institutions of higher education including the National University, University Putra Malaysia, University Malaya and a few other private colleges which cater for students from all over the country. The Klang Valley is also a popular location for local citizens to migrate to, as there are a lot of job opportunities available there, both in the government and private sectors. All these factors contribute to make it the best location to encounter a mixture of respondents coming from all the 14 states of Malaysia.

Initially, a total of 500 self-administered questionnaires were distributed at random to respondents satisfying the inclusion criteria of being Malaysian, of sound mind, literate and aged 18 years and above. The respondents were approached personally or in groups.

Before the questionnaire was distributed, the respondents were asked for their consent to be involved in the study. The purpose and consequences of the study were also explained to them. Most of the respondents were from local universities and hospitals. A lot of the questionnaires were distributed during organ donation campaigns organized by the National Transplant Registry (NTR) in collaboration with the National Blood Bank. These campaigns not only recruited more registered potential organ donors but also increased the chance of getting existing registered organ donors to answer the questionnaires, as registered organ donors are typically keener to donate blood compared to non-organ donors. Earlier, the questionnaires had also been reviewed by the University of Southampton Research Governance and Ethics Division as the study involved human participation.

The response rate for the study was very good, at 96.4%, with 482 completed questionnaires collected and analysed. The fact that the researcher was willing to wait for the questionnaires while they were being completed helped to ensure a high response rate. However, this did not affect the answers given by the respondents, because the researcher did not interfere at all in this process and waited from a distance. The remaining 18 completed questionnaires had to be excluded as five were invalid due to locality factors. Here, five Indonesians, whose physical appearance was very similar to that of Malaysians, had mistakenly taken part in answering the questionnaire. Their responses were rejected and considered void. The remaining 13 questionnaires were not returned to the researcher at all.

Besides that, data and information were also gathered from five series of interviews conducted with experts, including with Dr. Zakaria Zahari, Head of Department of Paediatric Surgery, Kuala Lumpur General Hospital, Dr. Ghazali Ahmad, Head of Nephrology Department Kuala Lumpur General Hospital, Dr Lela Yasmin Mansor, Chief National Transplant Coordinator and Jamaliah Kario, the Senior Transplant Coordinator. All the interviews were conducted separately and scheduled earlier, depending on the availability and at the convenience of the interviewees. The interviewees were selected based on their expertise and great contribution to the development of organ

transplantation activities in Malaysia. Generally, their views provided a close insight into the issue, not only from the medical perspective, but also in understanding the real scenario unfolding in Malaysia. The last interview, conducted with Prof. Dato' Dr Abdul Shukur Hj Husin, Chairman of the National Fatwa Committee Malaysia, managed to clarify the Islamic perspective on organ donation and transplantation in general and as applied in Malaysia. All the interviews took place at the interviewees' offices and were recorded on a cassette player, with their knowledge and consent. All relevant information obtained from the interviews is discussed and quoted throughout the thesis wherever suitable as the interviewees agreed to be identified and for their quotations to be used throughout the thesis.

The thesis is divided into eight chapters, with chapter one laying down the general foundation of organ donation which includes elaboration on its nature, justifications, history and development.

Chapter two highlights a few legislative systems already introduced worldwide to increase the number of human organs available for organ transplantation purposes. This includes the opting-in system, the opting-out system, organ conscription, organ trading, the required request system and, lastly, the mandated choice system. The chapter deliberates on how these systems function in different country settings, and whether they are beneficial in helping to reduce organ shortage problems.

Chapter three focuses on the practice of organ donation in Malaysia, including elaborating on the different legal procedures applicable in living and cadaver donations. This includes an analysis of the Human Tissues Act 1974 and the National Organ, Tissue and Cell Transplantation Policy, aiming to identify any existing weaknesses and suggest any necessary improvements. Local challenges faced are also highlighted; these evolve from the social, legal and religious restrictions.

Chapter four lays down the details and results obtained from an empirical study relating to organ shortage problems in Malaysia, which was conducted in the Klang Valleys,

specifically in Kuala Lumpur and the district of Hulu Langat between December 2007 and February 2008, involving 482 respondents from the public. The results from the study generally reflect Malaysians' perspective on organ shortage issues.

Next, in chapter five, the possibility of utilizing cadaveric organ donations as a solution to the organ shortage problem, while looking into the advantages it offers compared to living donations, is highlighted. A discussion on the concept of brain death is included as misunderstandings about this have often affected people's willingness to allow cadaveric organ donations to take place. The chapter also raises the issue of whether the authority to decide on organ donation should be passed to others, besides the individual him/herself, particularly when the deceased has left no clear wishes about it. Finally, the chapter justifies why the "opting-out" system is not yet suitable for application in Malaysia.

Chapter six elaborates on a suggested solution involving the large number of severe road traffic accidents taking place in Malaysia; this factor could be generated into becoming a potential source for the required supply of human organs. The positive and negative impact of the suggestion is discussed at length, while comparing it with the practice in other countries.

In chapter seven, the Islamic perspective on organ donation is included. This is to provide clarification that organ donation is actually permissible and approved by Islam, despite the reluctance and rejections expressed by a minority group of Islamic jurists. Other related issues discussed include the Islamic view on organ trading, cadaver and living donations, the brain death concept and living wills. The suggestion of utilizing organs from victims of road traffic accidents as a potential solution to organ shortage problems is also discussed in the light of recent Islamic rulings, to assess its potential acceptance within the religious framework.

Lastly, chapter eight concludes the thesis by discussing practical and potential solutions, suggested to help solve organ shortage problems in Malaysia. This concluding chapter elaborates how there is still plenty that can be done to solve the organ shortage in Malaysia rather than simply changing to the opting-out system as suggested by some.

CHAPTER 1

THE NATURE OF ORGAN DONATION

INTRODUCTION

This chapter will start with the general concept of organ donation which includes basic facts about the nature and justifications of such donations taking place worldwide. A general discussion of the history and development of organ donation, with specific focus on the development in Malaysia, is also included for further appreciation of the issue. Lastly, in the light of arguments justifying organ donation, we will also see how the organ shortage problem is becoming a barrier that to it progressing maximally.

1.1 THE CONCEPT OF ORGAN DONATION

Organ donation is one of the miracles of modern medical science and is the best, if not the only, life-saving therapy for patients with end-stage failure⁴. It is a complex procedure that makes use of body parts derived from human beings for the treatment of others. An individual or surrogate will voluntarily make a choice to allow that individual's viable organs to be given as a gift to a transplant patient, either ante-mortem or posthumously⁵. If the decision to donate is taken by the surrogate, it is typically made with the understanding that the decision is according to the would-be donor's wishes for how his or her body ought to be treated⁶. Normally, transplantation is needed and resorted to when the recipient's organ has failed or has been damaged due to certain illnesses or injuries. Among organs suitable for donation are the liver, kidneys, pancreas, heart, lungs, eye corneas and a few others, including tissues such as blood vessels, tendons, skin, bone marrow and blood. Through organ donation, new hope and aspirations have been extended to many dying and chronically diseased patients, and thousands of valuable lives have already been saved. In the UK for instance, transplants are now so successful that, a year after surgery, 94% of kidneys in living donor transplants and 88% of kidneys

⁴ Lela Yasmin Mansor. *1st. Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005) p.1.

⁵ Thomas D. Harter, 'Overcoming The Organ Shortage : Failing Means and Radical Reform', (2008) HEC Forum 20 (2), 155-182, p.155

⁶ *Ibid*

from cadaver donors are still functioning well⁷. For liver transplants the success rate is 86%, and for heart transplants the success rate is 84%. For lung transplants the figure is 77%, while 73% of heart/lung transplants are still functioning well⁸. Comparatively, in Malaysia, up to 1 September 2010, 1377 lives have been saved through kidney donations received from living and cadaver donors⁹. These statistics clearly explain why organ donation continues to be practised in the medical world.

For an organ donation procedure to take place, medical and logistical characteristics must be analysed to find the best-matched potential recipient. This includes blood type, size of the organ and the relative distance between the donor and the recipient¹⁰. The level of medical urgency and the degree of immune system compatibility between the donor and the recipient must also match. All these requirements are necessary to avoid any post-operative tissue rejection and function failure¹¹. Another important ethical element that must be fulfilled in every donation is the obtaining of a valid, informed consent¹². The general principle that surgery cannot be carried out without the consent of the person to be operated on is as applicable to organ transplantation as to any other procedure. Both the donor and recipient must be informed about the nature of the organ donation procedure, other alternatives available, and the pre- and post-transplant treatment, including necessary drug regimens, physical therapy and continued medical care¹³. Therefore, the operation to remove the organ from the donor must have the donor's consent and even its placement into the recipient must also obtain the consent of the recipient¹⁴. So, whether a country applies an opting-in, an opting-out or any other system for procuring organs, the consent of the donor, particularly in cases of live transplants, is crucial to ensure its validity. Every donation must be totally free of coercion, over-

⁷ Success Rates', Organ Donation, <http://www.organdonation.nhs.uk>, viewed on 21 October 2010.

⁸ *Ibid*

⁹ 'Penderma Sebenar', National Transplant Resource Centre, <http://www.agiftoflife.gov.my>, viewed on 20 October 2010.

¹⁰ Interview on 12 February 2008 with Dr. Ghazali Ahmad, Consultant and Head of Nephrology Department, Kuala Lumpur General Hospital, Malaysia,

¹¹ *Ibid*

¹² Parturkar D, Legal And Ethical Issues In Human Organ Transplantation', (2006), 25 *Medicine And Law*, 389

¹³ *Ibid*

¹⁴ Jonathan Montgomery, *Health Care Law*. (United States, Oxford University Press, 2003) p.446.

persuasion, deception and acts of improper inducement¹⁵. Both patient and donor have rights that they should be informed of and they should understand the procedures involved in organ donation including all relevant clinical and ethical effects that might occur relating to the donation. It is only when all the conditions have been confirmed and adhered to that the donation procedures may proceed.

Generally, organs can be sourced from both living and non-living donors, who are also referred to as cadaveric donors. Cadaveric donations normally take place when the deceased has died in intensive care but artificial breathing and heartbeat have been sustained until the donated organs have been retrieved. This method has a greater success rate because the organs are maintained by oxygenated blood until removal. Among organs that could be taken from this group of donors are the heart, liver, kidneys, pancreas, intestine, tissues and even the whole body (multi-harvesting). On the other hand, although cadaver donors are preferable, organs procured from living donors are obviously healthier than cadaveric ones¹⁶. Living donations normally involve the donation of a person's organs or tissues while they are still alive and this normally involves donation of a renewable tissue, cell or fluid, for example blood and skin, or even an organ or part of an organ when the remaining organ can regenerate or take on the workload of the rest of the organ, for instance a single kidney donation, or partial donation of the liver, small bowel or pancreas¹⁷. However, in all cases of organ donation, regardless of whether the organs are obtained from living or cadaveric donors, time is always of the essence. Therefore, in all cases, these organs must be procured rapidly and transplanted into the recipient as soon as possible¹⁸. Before any organ procurement procedure takes place, doctors will ensure that the blood group and tissues are compatible to guarantee a higher chance of success, as well as screening for any transmittable diseases. The better the match, the greater the chance of a successful outcome and it is believed that people from the same ethnic group are more likely to be of a close match¹⁹.

¹⁵ Dunstan, G, 'The Ethics of Organ Donation'. (1997) 53(No.4) *British Medical Bulletin* p.923

¹⁶ Shaun D. Pattinson, *Medical Law And Ethics*, (Sweet & Maxwell, London, 2006), p.440

¹⁷ Jonathan Herring, *Medical Law And Ethics*, (Oxford University Press, Oxford, 2006), pp.362-364

¹⁸ *Ibid*, p.363

¹⁹ Sheila A.M. McLean and Laura Williamson, *Xenotransplantation Law And Ethics*, (Ashgate Publications, Aldershot, 2005), p.4

Some people with rare tissue types may only be able to accept an organ from someone of the same ethnic origin, which makes it desirable for people from different ethnic backgrounds to donate their organs²⁰.

The public's acceptance of and attitude towards organ transplantation varies. Some consider it a social duty to donate and wasteful not to, while others, who do not hold such strong views, consider helping ill people in society with no loss to oneself or the deceased as merely the right thing to do²¹. For some others, organ donation is considered more of a gift than a social duty, while many are also committed to it due to their feeling of empathy towards potential recipients or as a sense of celebration of their loved one 'living on'²². Actually, when death occurs, the deceased's body and soul are separated and the individual is incapable of reconstitution. So, as a result of the death, the person is considered to no longer exist, and he/she has no further use for his/her body. Often, however, to the bereaved family, the deceased's body remains a part of their loved one, explaining why some are reluctant to allow organ donation procedures to proceed, although they are aware that the body is a potential source of life for others. From the perspective of an organ recipient, obtaining the required organs would mean the world to them. These precious gifts of life are invaluable beyond comparison, although the recipients need to adjust themselves, accepting the new organ as part of their own body and not as a separate identity²³. It is believed that, compared to all other types of organ donation, the heart transplantation has the most dramatic impact on the recipient's life, perhaps because the heart is often treated as the keeper of life and the focus of feelings²⁴.

As to the organ donor's perspective, they might feel that they are passing on their identity or characteristics, and that the organ donated bears some personal stamp that is 'them',

²⁰ *Ibid*

²¹ Irene Carey and Karen Forbes, 'The Experience of Donor Families in the Hospice', (2003) 17 *Palliative Medicine*, 241-247, 244

²² *Ibid*

²³ Burra,P, De Bona,M, Germini,G, Canova,D, Masier,A, Tomat,S and Senzolo,M , 'The Concept of Quality of Life in Organ Transplantation', (2007) 39 *Transplantation Proceedings*, 2285-2287, p.2285

²⁴ *Ibid*, p.2286

albeit in a transposed form²⁵. Coincidentally, organ recipients often report powerful feelings of identification with their donors, having new attitudes, tastes, personality traits and certain bodily habits which are believed to have been acquired from the donor along with the donated organ²⁶. Nevertheless, a true experience of an actual living donor was to express a feeling of relief at having done something unambiguously useful, at a tolerable personal cost in terms of fear and pain, by proceeding with the organ donation intended²⁷. So, no matter from which perspective organ donation is viewed, all organs donated are undoubtedly a precious source of continued life, or even a start to a new phase in life, especially for patients in urgent need of them. Unfortunately, many still do not comprehend the importance of donating organs, and fail to realise that, despite the fact that thousands of organs are in demand each day, thousands of these precious organs are also sadly wasted. In an international poll of well-educated people regarding awareness and feelings about organ donation, results showed that, despite repeated campaigns aimed at promoting organ donation, many still fail to take the initiative to register as organ donors²⁸, compelling some countries to make organ donation a compulsory act rather than one done voluntarily (the different systems available for organ procurement will be discussed further in chapter 2 of the thesis). This attitude is evidenced by the long waiting list of potential organ recipients queuing hopelessly for the needed organs, while juggling their lives in the race against time.

In moulding people's perceptions of organ donation, the media play a very influential role. For example, in the early days of heart transplantation, transplant surgeons were described as 'human vultures' who insensitively removed organs from bodies even before 'real death' had occurred²⁹. However, those days have dramatically changed and, as part of their contribution to support campaigns for organ donation, the media have frequently

²⁵ Kathleen Liddell and Alison Hall, 'Beyond Bristol And Alder Hey : The Future Regulation Of Human Tissue', (2005) *Med Law Review*, 1 June, 13(170),

²⁶ Megan Crowley-Matoka and Margaret Lock, 'Organ Transplantation in a Globalised World', (2006) *Mortality*, Vol.11, No.2, May, 166-181, p.174

²⁷ Maggie Harris, 'A Donor's Tale', (2008) *J Med Ethics*, July, Vol 34, No 5, 511-512, p.511

²⁸ Cantarovich F, Heguilen R, Filho MA, et al, 'An International Opinion Poll of Well Educated People Regarding Awareness and Feelings about Organ Donation for Transplantation', (2007) 20 *Transpl Int* , 512

²⁹ Margaret Brazier. *Medicine, Patients and the Law* (Great Britain, Penguin Books. 1987) p.272.

publicised touching stories on how organ donation has given more patients happiness and hope for better lives in the future. For instance, the story of Hannah Clark was initially published in the *Lancet*³⁰, reporting on the illness she had suffered since she was eight months old. Hannah presented with signs of severe heart failure and had to undergo heterotopic cardiac transplantation, in which the donor heart was placed in the right cavity and attached to Hannah's own heart to allow long-term reduction in her left ventricular pressure and consequently restore Hannah's real heart³¹. Now, after nearly 16 years, the heart transplant has proved to be a success and Hannah has become a fit young girl, capable of even running and swimming³². According to Professor Yacoub, the surgeon who initially transplanted Hannah's heart, the public needs to be made aware of the current organ shortage problems³³, and undoubtedly the media have the power to do this. Similarly, in Malaysia, the story of a Chinese girl, Teh Hui Yee, also touched the hearts of the public after they came to know about her stressful moments waiting for a donated heart, which was highlighted massively through the media. Teh, whose life depended on a mechanical heart, was put on the Left Ventricular Assist Device (LVAD)³⁴ and was desperate to find a heart donor. A mechanical heart could only last for two years and hers had only two weeks left before it expired. However, thanks to the daily media blitz in the mainstream and vernacular newspapers and television focusing on her plight, several referrals and donations occurred within a very short period. Her story had also successfully increased the number of potential donors, when 25 potential heart donors became available within just two weeks³⁵. Luckily, Teh at last managed to find a heart donor just in time³⁶.

³⁰ Tsang, V, Yacoub, M, Sridharan, S, et al, 'Late Donor Cardiectomy After Paediatric Heterotopic Cardiac Transplantation', (2009) *The Lancet*, Vol.374, issue 9687, 1 August 2009-7 August 2009, 387-392

³¹ Daniel M Henderson, 'Girl is Healthy After Having Donor Heart Removed', (2009), 15 July, *BMJ*, 339:b2867

³² *Ibid*

³³ *Ibid*

³⁴ Lela Yasmin Mansor, Cadaveric and Tissue Donation, Fourth Report of the National Transplant Registry 2007, NTR Publications, http://www.mst.org.my/ntrSite/download/report_2007/chapter8- Cadaveric and Tissue Donation.pdf, p.170

³⁵ Rabiatul Adawiyah Koh Abdullah, 'Menyelamatkan Nyawa Penerima Organ', Utusan Online, 26 July 2009. www.utusan.com, viewed on 26 July 2009

³⁶ 'Keluarga Halang Derma Organ', Berita Minggu, 28 June 2009, 18-19.

1.2 THE HISTORY AND DEVELOPMENT OF ORGAN DONATION

Turning back to the past, history has indeed proved that organ donation has been practised for quite some time. Although, in the beginning, organ donation took place without any formal legal procedures being laid down, this activity has contributed to the currently well-developed procurement system. In 1991 the World Health Organisation (WHO) stated:

*“Over the past 30 years, organ transplantation has become a worldwide practice and has saved many of thousands of lives. It has also improved the quality of life of countless other persons...”*³⁷

Historically, transplantation of tissues from one person to another has been attempted since earliest times. Skin was the first tissue transplanted³⁸. Several apocryphal accounts of transplants had also been found to have occurred in early Greece and Egypt³⁹. Major skin transplants occurred during World War I when Harold Gilles made advances in tubed pedicle grafts, while still keeping the flesh connected from the donor site in Aldershot⁴⁰. It was not until the nineteenth century that transplantation of other tissues from one person to another was attempted. It has been claimed that the first successful bone transplant took place in 1878⁴¹. The first attempted human deceased-donor transplant was performed by a Ukrainian surgeon named Yu Yu Voronoy in the 1930s. However, due to several factors, this attempt resulted in rejection and failure⁴². Before World War II, transplantation was resorted to only intermittently and was mainly focused on skin-grafting, principally because the body rejected foreign tissues and this rejection factor was not understood until World War II⁴³. A cornea transplant was then first

³⁷ WHO (1991), Human Organ Transplantation, WHO: Geneva. Quoted in Sheila, A.M. McLean and Laura Williamson, *Xenotransplantation Law and Ethics* (Great Britain, Ashgate Publishing p.1

³⁸ Russell Scott, *The Body As Property*. (Canada, The Viking Press, 1981) p.18

³⁹ *Organ Transplantation*. <http://neverland.ncssm.edu/~bhansalis/donation.html>. viewed on 8 June 2007

⁴⁰ *Ibid*

⁴¹ *Ibid*

⁴² Russell Scott, *The Body as Property* (Canada, The Viking Press, 1981) p.18

⁴³ Russell Scott, *The Body as Property* (Canada, The Viking Press, 1981) p.19

reported in Moravia as long ago as 1905 although, officially, most transplants took place in the second half of the 20th Century⁴⁴ .

In 1954, Dr. Joseph Murray successfully carried out the first ever kidney transplant operation on identical 23-year-old twins Richard and Ronald Herrick at the Peter Bent Brigham Hospital in Boston. This operation managed to prolong Richard's life for another eight years. In 1960, Sir Michael Woodruff carried out the UK's first kidney transplants on twin brothers at the Royal Infirmary of Edinburgh. They both lived for another six years before dying from a disease unrelated to the transplant that they had received earlier⁴⁵. The first liver and lung transplants were later performed in 1963 in the United States, although the recipient died within three weeks of the procedure's completion⁴⁶ .

A human heart transplant was first attempted in 1964 in Jackson, Mississippi, where a chimpanzee's heart was used as a substitution. Unfortunately this failed. Only three years later, Dr. Christiaan Barnard succeeded in carrying out the world's first heart transplant at the Groote Schuur Hospital in Cape Town, South Africa. The recipient was 55-year-old Louis Washkansky who had diabetes and incurable heart disease. He received the healthy heart of a young dead woman. Though the transplantation operation succeeded, Washkansky lived for just another 18 days and in the end died of double pneumonia⁴⁷. Nowadays, with advances in immunosuppressive therapy and improved surgical techniques, the success rate of graft survival at one year, five years and ten years post-transplant has also improved, allowing transplant surgery to be performed even on patients who would have been deemed unsuitable for transplant in the past⁴⁸ .

⁴⁴ History of Transplants. http://www.bbc.uk/health/donation/factfilesod_history.shtml.viewed on 8 June 2007.

⁴⁵ *History of Transplants*, http://www.bbc.co.uk/health/donation/factfilesod_history.shtml, viewed on 8 June 2007

⁴⁶ Russell Scott, *The Body as Property* (Canada, The Viking Press, 1981) p.19

⁴⁷ *Ibid*

⁴⁸ Lela Yasmin Mansor. *1st. Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005) p.1.

1.3 THE HISTORY AND DEVELOPMENT OF ORGAN DONATION IN MALAYSIA

In Malaysia, organ donation eventually started to become an accepted treatment to save lives. Having a majority of Muslim citizens, the government of Malaysia had to initially seek clarification on whether Islamic teachings permit such practice among Muslim believers. Thus, the National Fatwa Council was referred to and asked to check on its admissibility before it could be resorted to as part of the medical treatments offered. After thorough research on the matter, the National Fatwa Council later confirmed that organ donation and transplantation was permissible according to the Islamic teachings. Therefore, an official *fatwa*⁴⁹ was released in June 1970 to clarify and confirm the matter. The *fatwa* acknowledged that organ donation and transplantation is permitted in Islam and can be resorted to as an alternative treatment for organ failure cases⁵⁰. The fatwa confirmed, among other things, that:

“Cadaveric transplant of the eye and heart is permissible if the following conditions are observed:

- In the case of extreme need and urgency, in which the life of the receiver depends on that organ, and there is sufficient evidence that the transplant process will be successful.*
- In the case of heart transplantation, the death of the donor must be determined before the transplant can be performed. Proper action must be undertaken to ensure that there is no killing and trading of organs involved.”*⁵¹

Even though the only organs sanctioned in this fatwa are the eye and heart, other organs may also be included⁵². So, this fatwa made it clear that organ donations from cadavers

⁴⁹ The word ‘Fatwa’ derives from an Arabic word ‘fatawa’ which means religious rulings made by consensus of religious scholars especially in new matters on which clear rulings are not found in the main sources

⁵⁰ ‘Fatwa Derma Organ’ *Utusan Malaysia Online*, 21st. November 2006
http://www.utusan.com.my/utusan/archive.asp?y=2006&dt=1121&pub=utusan_mala viewed on 2nd April 2007

⁵¹ The fatwa announced by the Fatwa Committee on Islamic Affairs Malaysia in its first meeting on 23-24 June 1970, cited and translated from the “Pemindahan Organ Di Dalam Islam Fiqih dan Perlaksanaan Di Singapura, (Singapore, Office of the Mufti Strategic Unit, Islamic Religious Council of Singapore, 2007), p.41.

are permissible for Muslims as long as there are no elements of selling and bargaining involved, and it is the only alternative treatment possible to save the patient's life. The transplantation itself must never become a cause of death to any living donor as one life cannot be sacrificed to help save the life of another. That is why the donation of a heart can only take place after the donor's death and never before that.

At last, five years after the fatwa permitting organ donation and transplantations for Muslims was released, historically the first ever living related renal transplant took place at the Kuala Lumpur General Hospital on 15 December 1975⁵³. This was later followed by the first cadaveric renal transplant on 1 June 1976. Soon afterwards, more kidney transplants continued to take place; most of the kidneys were from living related donors (including emotionally related) and only a few were from cadaveric donors⁵⁴. Now, an average of 40 to 60 kidney transplants are performed annually (2 per million of the population per year) and this has not changed since the 1980s although the number of renal failure patients keeps increasing each year⁵⁵.

Liver transplant programs started in 1995 in Subang Jaya Medical Centre but were limited to living donor paediatric liver transplants. Only recently, in April 2002, did the Selayang Hospital, which has been designated as a Transplant Hospital, start its liver transplant service with a living related transplant, which was immediately followed by the first cadaveric liver transplant in the country⁵⁶.

The first heart transplant took place on 18 December, 1997, and this was carried out exclusively at the National Heart Institute (IJN)⁵⁷. As for cornea transplantation, this has been practised since the early 1970s, with corneas sourced from Sri Lanka. Today, corneal graft surgeries are widely performed by ophthalmologists throughout the country, both in government and private hospitals, using corneas obtained from Sri Lanka, USA

⁵² *Ibid*

⁵³ Lela Yasmin Mansor. *1st. Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005) p.1.

⁵⁴ *Ibid*

⁵⁵ Lela Yasmin Mansor. *1st. Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005) p.1.

⁵⁶ *Ibid*

⁵⁷ *Ibid*

and local cadaveric donors⁵⁸. Bone marrow transplants started in 1987, initially for paediatric patients and later for adults as well⁵⁹. Recently, it has become possible for haematopoietic stem cells to be harvested both from blood as well as bone marrows for the purpose of transplantations. Malaysia has also established its own National Tissue Bank in July, 1991, at the School of Medical Sciences, Health Campus University Science Malaysia, Kelantan. The bank functions by collecting, processing, storing and distributing tissues such as bone, skin and amnion from both human and animal sources, to be used by surgeons nationwide as biomaterial or tissue grafts to replace diseased tissues. There are also bone banks established at the Kuala Lumpur General Hospital and University Malaya Medical Centre. A cardiovascular tissue bank was also set up in IJN in 1995 to retrieve and prepare cardiac homografts which are needed particularly in paediatric cardiac surgery for repair of congenital heart defects⁶⁰.

1.4 JUSTIFYING ORGAN DONATION

Donating organs for those in need is a noble act, but there are both positive and negative effects emanating from each procedure carried out. Basically, organ donation not only ensures the survival of individuals with end-stage organ failures but also offers patients the chance to regain the health they had enjoyed before they were affected by the disease, achieving a good balance between the functional efficacy of the organ donated and the patient's psychological and physical integrity⁶¹.

Organ donation can gracefully offer patients prolonged survival and an improved quality of life⁶². There are cases where, for certain medical reasons, some patients are no longer able to continue with their dialysis treatment; thus, a transplant must be done as soon as possible to help save their lives. Added to the advancements in science and technology, where surgical techniques and new immunosuppressive drugs have improved, it has been

⁵⁸ *Ibid*, p.2

⁵⁹ *Ibid*

⁶⁰ Lela Yasmin Mansor. *1st. Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005) p.1-2.

⁶¹ Burra,P, De Bona,M, Germini,G, Canova,D, Masier,A, Tomat,S and Senzolo,M 'The Concept of Quality of Life in Organ Transplantation', (2007) 39 *Transplantation Proceedings*, 2285-2287, p.2285.

⁶² Rashad S. Barsoum, 'Trends in Unrelated-Donor Kidney Transplantation in The Developing World', (2008) 23 *Pediatr Nephrol*, 1925-1929, p.1925

possible to perform organ transplants on increasing numbers of patients with excellent results in terms of survival⁶³. This increase in the number of transplant recipients has even formed a new sociomedical community of “transplanted people”, characterised not only clinically, but also by specific psychopathological features⁶⁴. In the UK, patient survival rates in adult recipients demonstrate that the one-, two- and five-year survival rates are increasing if not being at least maintained⁶⁵. For adult recipients, the five-year kidney graft survival rates are 83%, 76% and 88% for living, deceased heart-beating and deceased non-heart-beating donations, respectively⁶⁶. For cardiac transplantation, patient survival is 81% at one year and 72% at five years. The corresponding figures for lung transplantation are 75% at one year and 54% at five years⁶⁷. The one- and five-year patient survival rates following deceased heart-beating donor liver transplantation are 89% and 75%, respectively. The one-year graft survival rates for pancreas and simultaneous kidney and pancreas transplants are 69% and 88%, respectively. The one- and five-year corneal graft survival rates following a penetrating keratoplasty are 93% and 69%, respectively⁶⁸. However, there is always the risk that organ rejection might cause the organ donation procedure to fail, particularly when the recipient’s body refuses to accept the new tissue implanted within it⁶⁹. If the donor and recipient have similar biological features, such as blood type or ethnic group, the risk of rejection might not be too high. But the greater the dissimilarities between them the more intense will be the reaction⁷⁰. The degree of rejection also varies according to the organs involved; for example, rejection is more likely to happen with transplanted hearts, kidneys, glands, lungs and pancreas, compared to cornea and cartilage transplants⁷¹. However, these risks of organ rejections can be treated by providing immunosuppressant drugs. And although

⁶³Burra,P, De Bona,M, Germini,G, Canova,D, Masier,A, Tomat,S and Senzolo,M , ‘The Concept of Quality of Life in Organ Transplantation’, (2007) 39 *Transplantation Proceedings*, 2285-2287, p.2285

⁶⁴ *Ibid*

⁶⁵ Dave Collett, NHS Blood and Transplant. Transplant Activity in the UK 2007-2008, http://www.uktransplant.org.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/transplant_activity_uk_2007-2008.pdf, viewed on 12 October 2009.

⁶⁶ *Ibid*

⁶⁷ *Ibid*

⁶⁸ *Ibid*

⁶⁹ Russell Scott, *The Body as Property* (Canada, The Viking Press, 1981) p.48

⁷⁰ J.K Mason & R.A.Mcall-Smith. *Butterworths Medico-Legal Encyclopaedia*. (London, Butterworth,1987) p.561

⁷¹ Russell Scott, *The Body as Property* (Canada, The Viking Press, 1981) p.52

there might be problems such as prolonged wound pain or depression after the operation, these are not serious as they will normally cease as time passes.

In terms of financial costs, although organ transplantation procedures are expensive they are still considered cost-effective compared with dialysis⁷². Normally, a kidney failure patient will be attached to a dialysis machine a few times weekly, and the patient is totally dependent on the machine throughout his/her lifetime. However, kidney donation is economical⁷³, and provides relief from high-impact socioeconomic burdens⁷⁴, as it only incurs one-shot operational costs and immunosuppressant drugs. Research conducted in Spain pertaining to the costs involved in both treatments estimated that renal replacement therapy costs almost twice the total cost of all solid organ transplants performed⁷⁵. Similarly, in the US, the cost of dialysis is three times the cost of a kidney transplant over a 4-year period⁷⁶. In the UK, it is estimated that the National Health Service (NHS) will save up to £21,900 per annum if a patient has a kidney transplant rather than having dialysis⁷⁷. According to a European study, kidney transplantation for 1,000 patients saved 2 million euros⁷⁸.

Additionally, when debating cost-effectiveness, some may dispute whether it is worth spending so much money on organ donation procedures particularly when there is no guarantee that they will succeed. Moreover, even successful operations may only manage to prolong the patients' lives for one or two years more; in addition they are vulnerable to post-operational complications such as infections, bleeding, rejection of the organs and many other eventualities. The worst case is when the patients do not survive the operation

⁷² Aaron Spital, 'Should People Who Donate A Kidney To A Stranger Be Permitted To Choose Their Recipients? Views of The United States Public', (2003), *Transplantation*, Vol.76, No.8, 1252-1256, p.1252

⁷³ Walter Glannon, 'Underestimating The Risk in Living Kidney Donation', (2008) 34 *J Med Ethics*, 127-128, p.128

⁷⁴ Rashad S. Barsoum, 'Trends in Unrelated-Donor Kidney Transplantation in The Developing World', (2008) 23 *Pediatr Nephrol*, 1925-1929, p.1925

⁷⁵ Rafael Matesanz. 'Organ Donation in Spain'.

http://www.uktransplant.org.uk/ukt/newsroom/bulletin/current_bulletin/organ_donation.viewed on 20 March 2007

⁷⁶ Abouna, G.M 'Organ Shortage Crisis: Problems and Possible Solutions', (2008) 40 *Transplantation Proceedings*, 34-38, p.34

⁷⁷ UK Transplant 2004 cited from Jonathan Herring, *Medical Law and Ethics* (United States, Oxford University Press, 2006) p. 364.

⁷⁸ Abouna, GM, 'The Humanitarian Aspects of Organ Transplantation', (2001) 14 *Transplant International*, 117

procedures themselves. However, all these claims are refutable because, by having organ donations, at least we are not hopelessly yielding to fate. Before any organ donation procedures take place, every possible measure is taken by the treating surgeon, physicians and neurologists to weigh the degree of risks and benefit involved to ensure that the operation is worth carrying out⁷⁹. The surgeon must be convinced that the proposed procedure satisfies the risk or benefit assessment, and a substantial degree of latitude is afforded to the prospective donor⁸⁰. Safety of both the organ donor and recipient is the top priority to ensure that both of them will survive any possible complications that might take place post-operations, particularly in living donation cases.

Another challenge is to carry out as soon as possible any organ transplantation procedures scheduled. This is because these organs and tissues can deteriorate rapidly outside a working cardio-respiratory system. So, all operational procedures must commence almost immediately to prevent the available potential organs from being unusable and wasted. Luckily, nowadays, there are certain techniques available to prevent fast deterioration of these tissues and organs before and during transplantation. However, after a person has died, it is best to remove the kidneys within one hour and the corneas within 24 hours; as for the heart valves and tracheae, they can survive for up to 72 hours⁸¹.

Besides the financial impact and cost savings that it brings, organ transplantation is justifiable as it allows the waiting list of donees to be reduced. Although many countries currently face problems in meeting each and every request for an organ, by at least allowing and promoting transplantation to take place wherever possible, each country helps to reduce the numbers of those waiting hopefully for healthy organs. In the future, it is also predicted that demand for organs will increase due to a rapid rise in certain diseases such as diabetes and hepatitis C, together with an ageing population⁸². So, more

⁷⁹ Parturkar D, 'Legal And Ethical Issues In Human Organ Transplantation', (2006), 25 *Medicine And Law*, 389

⁸⁰ *Ibid*

⁸¹ Irene Carey and Karen Forbes, 'The Experiences of Donor Families in the Hospice', (2003) 17 *Palliative Medicine*, 241-247, p.241.

⁸² Organ Transplants. Parliamentary Office of Science and Technology (POSTNOTE). No.231, October 2004. www.parliament.uk/post. p.1

organs will be needed as a solution for this. Promoting organ donation will also indirectly secure a country's supply of potential human resources generally. As more lives are saved and prolonged, these people will hopefully be able to lead a good-quality, normal life and contribute their labour services to the nation. A brighter future awaits the recipients, although they must be constantly encouraged towards a more fulfilling and better quality of life⁸³.

1.5 THE ORGAN SHORTAGE CRISIS

Analogically, the human body is similar to a kind of machine; however, once essential body parts resembling the body organs start to fail, replacing them with another similar organ is not as simple as finding a match for a broken-down machine. It is a fact that organ transplantation procedures can extend people's lives, although various biological factors must also be taken into consideration. The limited supply of human spare parts is actually due to a limited supply of donors in the first place. Thus, this contributes to the problem of organ shortage which remains unresolved despite various methods and systems being introduced and applied to help combat this problem.

The global problem of organ shortage is the main barrier stopping many more patients benefiting from organ donation procedures and the cause of many more having to join long queues on the waiting list⁸⁴. This problem of organ shortage started to emerge in the mid-1980s, when people who needed organs had to wait for a very long time to get the required organs⁸⁵ and the demand for organs became far higher than the number of organs available. In other words, demand is soaring beyond supply. This was partly the result of successful achievements in organ transplantation procedures⁸⁶ and advanced medical technology which managed to control the rejection of the foreign human organ in a patient's body⁸⁷. Consequently, more patients began to favour this alternative cure for

⁸³ Burra,P, De Bona,M, Germini,G, Canova,D, Masier,A, Tomat,S and Senzolo,M, 'The Concept of Quality of Life in Organ Transplantation', (2007) 39 *Transplantation Proceedings*, 2285-2287, p.2287

⁸⁴ Larijini B, Zahedi F and Taheri E, 'Ethical and Legal Aspects of Organ Transplantation in Iran', (2004) 36 *Transplantation Proceedings*, 1241-1244

⁸⁵ Martine Rothblatt, *Your Life or Mine*, (England , Ashgate Publishing Limited, 2004) p. 2.

⁸⁶ First M.R, 'The Organ Shortage And Allocation Issues', (2001) 33 *Transplantation Proceedings*, 806-810, p.806

⁸⁷ *Illegal Human Organ Trade from Executed Prisoners in China*. p.1.

<http://www.american.edu/TED/prisonorgans.htm>. viewed on 5 March 2008

their diseases. Another cause for the shortage was the attitude of surgeons who became more selective in their search for quality organs since this would result in better survival rates for patients⁸⁸. In many countries the traditional source of organs for transplantation is from victims of road traffic accidents⁸⁹ who have sustained intracranial haemorrhages, and from patients dying from sudden catastrophic medical causes such as cerebrovascular accidents, acute respiratory failure and others⁹⁰.

However, the advent of rapid means of evacuating accident victims and the general improvement in resuscitation techniques have also resulted in a drastic reduction in the number of patients dying from injuries and consequently, fewer potential cadaver organ donors. Lastly, another major reason for the decline in the number of organs available for transplantation is the refusal of relatives of patients declared brainstem-dead to give consent for organ procurement⁹¹. Nowadays, the problem of scarcity remains as thousands of people all over the world still die each year while waiting to receive a new organ. In the UK for instance, up to the 1st April 2009, although 1,369 patients have received transplants, 8,131 people are still waiting hopefully for their transplant to take place⁹². Currently, according to the NHS Blood and Transplant (NHSBT), there are 7,986 people in the UK on the “active” waiting list for an organ transplant⁹³. This is not to mention the additional 2,300 who are on the “suspended” list because they are too ill or unable to receive a transplant at present; in total, there are more than 10,000 people needing an organ transplant in the UK alone⁹⁴. Sadly, in 2007/08, approximately 1,000 died after waiting in vain on the waiting list⁹⁵. This problem is causing more preventable deaths and suffering among innocent chronic patients although around 90% of UK

⁸⁸ Martine Rothblatt. *Your Life or Mine*. (England, Ashgate Publishing Limited, 2004) p. 2.

⁸⁹ Shaun D. Pattinson, *Medical law and Ethics*, (Sweet & Maxwell, London, 2006), p.421

⁹⁰ Briggs J.D, Crombie A, Fabre J, et al, ‘Organ Donation in the UK : A Survey By A British Transplantation Society Working Party’, (1997) 12 *Nephrol Dial Transplant*, 2251-2257, p.2251

⁹¹ Kehinde, E.O, ‘Attitude to Cadaveric Organ Donation in Oman: Preliminary Report’, (1998) *Transplantation Proceedings*. Volume 30 Issue 7 November 1998, Pages 3624-3625

⁹² NHS Blood and Transplant. Transplant Save Lives, <http://www.organdonation.nhs.uk/ukt/default.jsp>, Viewed on 20 October 2009.

⁹³ News Release, 8 October 2009, Reform of Organ Donation and Transplantation Service is Helping to Save More Lives, <http://www.nhsbt.nhs.uk/news/2009/newsrelease081009.html>, Viewed on 20 October 2009.

⁹⁴ *Ibid*

⁹⁵ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, para 2.1, p.6

citizens are in favour of organ donation⁹⁶. The UK still falls near the bottom of the league table of European countries in terms of donor rates, with just 13 donors per million of population⁹⁷. Approximately 1 patient on the UK transplant list dies every day while waiting for an organ donor⁹⁸, and this waiting list is growing rapidly by 8% a year⁹⁹. The number of patients on the active and suspended transplant list reached 7963 in 2008, compared to only 5396 in 1999¹⁰⁰.

In the United States, one patient is added to the waiting list every 15 minutes¹⁰¹. In 2006, although 28,110 organ transplants were performed, including 6,896 from living donors, 6,342 patients still died while on the waiting list¹⁰². Later, in 2007, more than 95,000 patients were reported as still waiting for their transplants to take place¹⁰³. As a consequence of this global crisis, patients with vital organ failure are deprived of a new life; others with non-vital organ failure are deprived of life extension¹⁰⁴. From an economic point of view, as more of these precious lives could not be saved, more valuable human resources are being continuously wasted.

Focusing on Malaysia, the demand for organs is also high although it varies according to type. It is believed that shortage of these organs is not primarily the result of a lack of suitable donors but is rather the consequence of failure to identify potential donors and turn them into actual ones, obtaining consent, and other weaknesses in the administration of the existing procurement system. Other factors, such as misunderstanding certain religious and cultural values, lack of awareness, and family objections undoubtedly contribute to the problem. Although the waiting list for organs is endless, unfortunately

⁹⁶ *Ibid*

⁹⁷ Emma Wilkinson, 'UK Government Plans Shake-Up of Organ Donation Services', (2008) *The Lancet*, vol.371, January 26

⁹⁸ Chief Medical Report 2006, <http://www.dh.gov.uk>, Viewed on 1 October 2010, pg 28

⁹⁹ Amber Rithalia, Sara Suekarran, Lindsey Myers and Amanda Sowden, 'Impact of Presumed Consent for Organ Donation on Donation Rates : A Systematic Review', (2009) *BMJ* 338:a3162

¹⁰⁰ Number of Deceased Donors and Transplants in the UK, 1999-2008 and Patients on the Waiting and Suspended Transplant Lists at 31 December, <http://www.organdonation.nhs.uk>, Viewed on 1 October 2010.

¹⁰¹ United Network for Organ Sharing:OPTN Report, 9 February 2007

¹⁰² *Ibid*

¹⁰³ Abouna, GM, 'Organ Shortage Crisis: Problems and Possible Solutions', (2008) 40 *Transplantation Proceedings*, 34-38, p.34

¹⁰⁴ *Ibid*

not many local organs are made available, forcing patients to purchase organs for transplantation at their own cost from other countries such as China and India¹⁰⁵. This scenario is worrying, as an estimated 2,500 chronic patients are added to the waiting list each year¹⁰⁶.

In 2005, Malaysia witnessed declines in the number of potential donor referrals made to the National Transplant Procurement and Management Unit (NTPMU) and the number of actual organ and tissue donations made. From a total of 62 potential donor referrals, in the end only 13 became actual donors¹⁰⁷. This resulted in a very low rate of only 0.53 per million of population¹⁰⁸. In 2006, however, there was a marked increase in the number of potential donors referred to the NTPMU; from 112 potential donor referrals made, 25 actual donations materialised, although this increase was still not sufficient to meet the high demand for organs nationwide¹⁰⁹. The positive increase did not last long as, in 2007, a decline was again reported in the number of potential cadaveric donors referred to the NTPMU nationwide, dropping significantly to only 73 referrals. However, the number of actual donors remained the same at 25, which translated into a donation rate of 0.99 per million of population (pmp)¹¹⁰. Data from these three consecutive years clearly show that there has been no improvement in the number of actual organs obtained, meaning that the organ shortage problem is still unresolved.

Accordingly, over the past twenty years, as the number of cadaveric organs, particularly kidneys and cornea donations, were very few and far between, the transplant team was only required to manage cases on an ad hoc basis, particularly whenever there were any

¹⁰⁵ Puteri Nemie Kassim, 'Organ Transplantation in Malaysia: A Need for a Comprehensive Legal Regime', (March 2005), 24(1) *Med Law*, 173-189.

¹⁰⁶ Nurul Anuar Kari. 'Takut Derma Organ-9000 Pesakit Terpaksa Menunggu Ganti Buah Pinggang'. *Utusan Online*. 1 November 2006 viewed on 2 April 2007.

¹⁰⁷ Lela Yasmin Mansor, 2nd. *Report of the National Transplant Registry 2005*, (Kuala Lumpur, National Transplant Registry, 2006), p.151.

¹⁰⁸ *Ibid*

¹⁰⁹ Lela Yasmin Mansor, 'Cadaveric Organ and Tissue Donation', Third Report of the National Transplant registry 2006, [http://www.mst.org.my/ntrSite/download/report 2006/Introduction_NTR2008final.pdf](http://www.mst.org.my/ntrSite/download/report%202006/Introduction_NTR2008final.pdf). Viewed on 25 August 2009.

¹¹⁰ Lela Yasmin Mansor, *Fourth Report of the National Transplant Registry 2007*, (Kuala Lumpur, National Transplant Registry, 2007), p.170.

organs available¹¹¹. Currently, only about 40 to 60 kidney transplants are done annually, which represents 2 pmp per year, and this situation has remained the same since the 1980s¹¹². This fact contributes to the significant increase in the number of renal failure patients going onto dialysis therapy, from 33 pmp in 1995¹¹³ to 101 pmp in 2005¹¹⁴. This suggests that less than 6% of end-stage kidney failure patients receive transplants and the vast majority will have to accept lifelong dialysis therapy as their only available option¹¹⁵. Therefore, due to this severe shortage in kidney supply, many patients have resorted to having their transplants done commercially overseas in countries such as China, where commercial cadaveric transplants are the main source of kidney supply, and India, where the required kidneys are procured from commercial living unrelated donors¹¹⁶, including from Pakistan and the Philippines¹¹⁷. There is also a shortage in the supply of hearts; for example, up to 2004, it was reported that 31 patients had died while waiting for a suitable heart donor¹¹⁸.

Although Malaysia faces a huge challenge to increase the number of actual donors, the number of registered potential donors nevertheless seems to have stabilised in recent years. Statistics from the National Transplant Registry up to 31st August 2009 record that Malaysia had a massive number of 133, 496 registered organ donors; in contrast, however, only 256 have eventually become actual donors¹¹⁹. Similarly, for the year 2009 alone, up to 31st August 11,195 people had pledged to become organ donors, but only 24

¹¹¹ Hooi LS and Lela Yasmin Mansor, *1st.Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005), p.128.

¹¹² Tan Chwee Choon, *2nd.Report of the National Transplant Registry 2005*, (Kuala Lumpur, National Transplant Registry, 2006), p.1-2.

¹¹³ Lela Yasmin Mansor, *1st.Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005), p.3.

¹¹⁴ Tan Chwee Choon, *2nd.Report of the National Transplant Registry 2005*, (Kuala Lumpur, National Transplant Registry, 2006), p.1-2.

¹¹⁵ *Ibid*

¹¹⁶ Lela Yasmin Mansor, *1st.Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005), p.3.

¹¹⁷ Yahya Awang, Zaki Morad and Lela Yasmin Mansor, Foreword, Third Report of the National Transplant registry 2006, [http://www.mst.org.my/ntrSite/download/report 2006/Foreword](http://www.mst.org.my/ntrSite/download/report%202006/Foreword), Viewed on 25 August 2009.

¹¹⁸ Lela Yasmin Mansor, *1st.Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005), p.1.

¹¹⁹ National Transplant Registry, <http://www.agiftoflife.gov.my/>, viewed on 1 October 2009.

have actually fulfilled their intention and become actual organ donors¹²⁰. Therefore, based on the statistics above, it would be fair to conclude that Malaysia does not lack a large number of potential organ donors even though many more are neither participating nor taking initiatives to register as organ donors. However, most important of all, something appears to be hindering these potential organ donors in proceeding to become actual organ donors. This scenario also signifies that the existing measures are insufficient and not effective enough to ensure that enough organs are procured as expected, to meet the high demand for them. Perhaps the existing doubts and controversies about the actual practice of organ donation and transplantation procedures have affected the public's confidence, causing people to alternatively resort to the media for publicity and a rapid search for their required organs. It is suspected that all this contributes indirectly towards the organ shortage problem. And until clear information and knowledge is disseminated, these confusions and misunderstandings will remain part of society's way of thinking

1.6 CONCLUSION

Organ donation is not a new issue, although it is still struggling to win a place in everybody's heart. Some might think it an uncomfortable issue to ponder, perhaps due to its slightly negative consequences, but for others it might be the only hope left for survival and is worth trying. Additionally, the fact that history has shown how many lives have been saved through organ donation will be immaterial unless the public can really appreciate its importance. Until then, the problem of organ shortage will continue to pull us down; the supply of potential organs will remain insufficient, causing many more lives to be wasted unnecessarily.

¹²⁰ *Ibid*

CHAPTER 2

A REVIEW OF VARIOUS LEGISLATIVE SYSTEMS FOR ORGAN PROCUREMENT WORLDWIDE

INTRODUCTION

The organ shortage problem is being experienced globally, and various solutions have emerged to regularize the availability of the required organs. The scientific ideas suggested range from manufacturing artificial organs and medical devices from synthetic materials such as implantable “bio-machines” that replace or supplement the functions of failing tissues¹²¹, to growing new organs from one’s own differentiated cells through tissue engineering¹²², and even to providing a supply of humanised organs from animals by xenotransplantation technology¹²³. Cloning organs is another biotechnological possibility being considered though it is still far less certain how individuals’ bodies would respond to these cloned organs¹²⁴. So, although these technologies are constantly developing, they still have their own practical limitations and evoke various degrees of moral concern or condemnation¹²⁵.

Additionally, a few regulatory systems and pieces of legislation have been introduced and adopted in various countries to solve the same problem. This chapter will highlight a few of these legislative systems introduced to increase the number of human organs available for organ transplantation purposes. These will include the opting-in system, the opting-out system, organ conscription, organ trading, the required request system and, lastly, the mandated choice system. The discussions will deliberate on how these systems function

¹²¹ Shaun D. Pattinson, *Medical Law and Ethics* .(London, Sweet & Maxwell, 2006) p.459.

¹²² Jonathan Herring, *Medical Law and Ethics*, (Oxford, Oxford University Press, 2006), p.362.

¹²³ Sheila A. M. McLean and Laura Williamson, *Xenotransplantation Law and Ethics*, (Aldershot, Ashgate Publishing Limited, 2005), p. 41.

¹²⁴ Goodwin, Michele, *Black Markets The Supply and Demand of Body Parts*. (United States of America, Cambridge University Press, 2006), p.21.

¹²⁵ Shaun D. Pattinson. *Medical Law and Ethics*. (London, Sweet & Maxwell, 2006), p.419.

in different country settings, and whether they are useful in helping to reduce organ shortage problems.

2.1 THE OPTING-IN SYSTEM

The opting-in system, also commonly known as the ‘contracting-in’ system, permits tissue and organs to be posthumously removed for organ donation procedures, provided that a clear and informed consent has been obtained¹²⁶ expressly without any elements of speculation and assumptions involved. This opting-in system is classified into two types, namely the ‘narrow opting-in system’ and the ‘wide opting-in system’¹²⁷. The difference is that, in a narrow opting-in system, only the donor can provide consent for his/her organs to be removed upon death while, in contrast, a ‘wide opting-in system’ allows consent to be obtained from the donor and his/her surviving next of kin as well¹²⁸. Therefore, as the element of consent from the donor is considered significant, especially in the narrow opting-in system, the criteria of individual autonomy are accordingly fulfilled and every organ donated can be assumed to be made in the spirit of altruism.

a) The United Kingdom

The UK currently applies the opting-in system, although there is support to change to the opting-out system¹²⁹. Therefore, organs can only be taken from people who have legally established an effective consent¹³⁰. Subsequently their name will be put on the NHS Organ Donor Register which demonstrates that the person has agreed to become an organ donor and has consented for his/her organs to be used for transplantation¹³¹. Subsequently, the registered donor will be sent a donor card for easy identification¹³².

¹²⁶ Shaun D. Pattinson, ‘*Medical Law and Ethics*’, (Sweet & Maxwell, London, 2006), p.428

¹²⁷ *Ibid*, pp. 428-429.

¹²⁸ *Ibid*.

¹²⁹ John Harris, ‘Organ Procurement: Dead Interests Living Needs’, (2003) 29 *J.Med.Ethics*, 130-134

¹³⁰ Section 1 of the Human Tissue Act 2004 establishes that consent from the appropriate person as defined in section 2 and 3 of the same Act is required before any activities including the use of whole bodies, removal, storage and use of relevant material from the body of a deceased person, and storage and use of relevant material from a living person can be done,

<http://www.legislation.gov.uk/ukpga/2004/30/notes/devision>, viewed on 18 May 2011.

¹³¹ ‘What is the NHS Organ Donor Register?’, <http://www.organdonation.nhs.uk>, viewed on 1 September 2010

¹³² *Ibid*

Although it is advisable to carry the organ donor card at all times, it is normal for cards to become damaged or lost or they might not be carried with the donor when he/she is taken to the hospital. So, with the existing registration system, once a person registers his/her name on the Organ Donor Register, their wish to become an organ donor has already been secured, as all the required details and wishes have already been safely recorded on a National Database, maintained by NHSBT and available to the authorized medical personnel¹³³.

Later, the Chief Medical Officer's Report of 2006 initiated proposals to amend legislation by creating an opt-out system for organ donation, with proper safeguards and good public information, as the solution to the organ shortage crisis in the UK¹³⁴. Initially, Mr. Gordon Brown, the UK's Prime Minister at that time, also expressly supported a change in the organ procurement system when he commented that the opting-out system could potentially close the aching gap between the potential benefits of transplant surgery in the UK and the limits imposed by the current system of consent¹³⁵. However, the indication that he would willingly back the Spanish-style opting-out approach received various responses as, four years earlier, Gordon Brown and Alan Johnson, the Health Secretary, had voted against opting-out for organ donations on the basis that there was no public support; they believed that there were better ways to increase donations. They also mentioned that it was not for the state to determine what should happen to people's bodies after death¹³⁶.

The Liberal Democrat MP Dr. Evan Harris, chairman of the All-Party Kidney Group and a member of the British Medical Association's Medical Ethics Committee, positively described the Prime Minister's support for the opting-out system as "good news for patients, good news for potential donors and good news for their relatives"¹³⁷. The

¹³³ 'Organ & Tissue Donation-Your Questions Answered', No.14. Do I Need To Register If I Have A Donor Card?', <http://www.organdonation.nhs.uk>, viewed on 1 September 2010

¹³⁴ Chief Medical Officer Report 2006, <http://www.dh.gov.uk>, Viewed in 1 October 2010, pg.33

¹³⁵ 'Brown Backs Organ Donation Overhaul'. *Daily Express*. 12 January 2008
<http://www.express.co.uk/posts/view/31274/Brown-backs-organ-donation-overhaul> viewed on 12 April 2008.

¹³⁶ Philippe Naughton, 'Tories Criticise Brown on Organ U-Turn'. *Times Online*. 13 January 2008.
<http://www.timesonline.co.uk/tol/news/politics/article3180510.ece>. viewed on 12 April 2008.

¹³⁷ *Ibid.*

Liberal Democrat Health spokesman, Norman Lamb, was also delighted with this positive development as, according to him, more potential lives could be saved through this system although, at the same time, it was essential to ensure that the ability to opt out of the system was a genuine one and no families should feel that such a step was being taken against their will¹³⁸. Junior Health Minister Ben Bradshaw further added that the proposals could save thousands of lives and further reduce medical costs¹³⁹. However, despite the support, many were opposed to this stunning development.

John Fabre, the past president of the British Transplantation Society, argued that there is no conclusive evidence that presumed consent works¹⁴⁰. Fierce opposition was also expressed by patients' groups and the Shadow Health Secretary, Andrew Lansley, who opined that it was not for the state to decide what should happen to peoples' organs after death. He further emphasised that the government's responsibility is to encourage registration and ensure transplant co-coordinators and transplant nurses are in place so that, when organs are made available, they can be used for transplants¹⁴¹. Joyce Robins of the Patient Concern Watchdog was equally opposed to the suggestion of turning to opting out; in her view, although the system is alternatively called 'presumed consent', there is in reality no element of consent involved at all¹⁴².

Following the Chief Medical Officer's recommendation in his annual report for 2006, and the various reactions to it, the Secretary of State for Health, Alan Johnson, asked the Organ Donation Taskforce chaired by Elisabeth Buggins to examine how organ donation and transplant rates could be improved¹⁴³. The Taskforce consulted and sought an enormous range of opinions from various levels of society including academics, health professionals, laymen, organ recipients, families of donors and faith leaders before

¹³⁸ *Ibid.*

¹³⁹ 'Brown Backs Organ Donation Overhaul'. 12 January 2008. *Daily Express*.
<http://www.express.co.uk/posts/view/31274/Brown-backs-organ-donation-overhaul> viewed on 12 April 2008.

¹⁴⁰ Nigel Hawkes, 'Organ Supply 'Can Be Boosted Without New Law'. 17 January 2008. *The Times*.
<http://business.timesonline.co.uk/tol/business/law/article3200361.ece> viewed on 12 April 2008

¹⁴¹ Philippe Naughton. 'Tories Criticise Brown on Organ U-turn'. 13 January 2008 *Times Online*.
<http://www.timesonline.co.uk/tol/news/politics/article3180510.ece>. viewed on 12 April 2008

¹⁴² *Ibid*

¹⁴³ Organ Donation Taskforce, <http://www.nationalarchives.gov.uk>, Viewed on 1 October 2010

suggesting the solution¹⁴⁴. As a result, in January 2008 the taskforce proposed 14 recommendations including suggestions for doubling the number of front-line transplant co-coordinators, strengthening the network of organ retrieval teams, identifying potential donors sooner, providing mandatory training of critical-care staff and promoting organ donation extensively by using the 11 million pounds of funding provided¹⁴⁵. And most important of all, the Taskforce, in its later report released in November 2008, managed to reach a clear consensus in recommending that an opting-out system should not be introduced in the UK at the present time; if the donor numbers do not grow by 50% by 2013, despite all the 14 recommendations being implemented, only then should the issue of shifting to opting out be reconsidered¹⁴⁶.

2.2 THE OPTING-OUT SYSTEM

The opting-out system presumes the consent of the potential donor to be in existence upon the death of the deceased party unless an objection has been registered earlier¹⁴⁷. The law could permit organs to be procured, unless the person explicitly opts out of such a commitment¹⁴⁸. This means that the government and procurement organisations may assume that citizens are willing to donate their organs at death if they do not state otherwise¹⁴⁹. ‘Presumed consent’ or ‘contracting out’ are other terms for this arrangement. However, there is a view that the term ‘presumed consent’ is something of a misnomer in medical care, because consent is supposed to be an active process where permission is given expressly by a patient for a procedure to be carried out on their

¹⁴⁴ Elisabeth Buggins, *The Potential Impact Of An Opt Out System For Organ Donation In The UK*, An Independent Report From The Organ Donation Taskforce, p.3

¹⁴⁵ Bruce Keogh, Letter to all Trust Chief Executives on Organ Donation Taskforce ‘Organs for Transplants’ Implementation of The Organ Donation Taskforce Recommendations, 17 April 2008

¹⁴⁶ *The Potential Impact Of An Opt Out System For Organ Donation In The UK*, An Independent Report From The Organ Donation Taskforce, pp.33-35

¹⁴⁷ Veatch RM and Pitt JB, ‘The Myth of Presumed Consent: Ethical Problems in New Organ Procurement Strategies’ in Veatch RM, ed, *Transplantation Ethics*, (Washington DC, Georgetown University Press, 2000, pp. 167-174

¹⁴⁸ Amitai Etzioni, ‘Organ Donation : A Communitarian Approach’, (2003) *Kennedy Institute of Ethics Journal*, Vol.13, No.1, 1-18, p.2

¹⁴⁹ Sam Crowe and Eric Cohen. *Organ Transplant Policies and Policy Reform*. www.bioethics.gov/background/crowepaper.htm. viewed on 12 January 2008.

body¹⁵⁰. Valid consent is necessary to avoid any possibility of the clinical staff being guilty of an assault on the particular patient. Therefore, if the patient lacks capacity and is unable to give consent for vital invasive procedures, the doctors would be acting on their own judgement of the patient's 'best interest', and not actually on 'a presumption' of consent'¹⁵¹. Currently, at least 13 European countries, including Spain, Austria, Portugal and Belgium, have adopted this opting-out system¹⁵², which is further classified into two types:

- a) The hard (wide) opting-out system;
- b) The soft (narrow) opting-out system.

The hard opting-out system relies solely on the individual citizen to declare him/herself a non-donor while, in some legislations, the soft opting-out system also allows the family members of the deceased to opt out on their behalf, either in the best interest of the deceased or if they themselves prefer to do so, depending on the particular legislative scheme applicable¹⁵³. In other words, in the hard opting-out system, an objection to the removal of organs can only be made by the deceased prior to his/her death but, in the latter system, objections may also come from the surviving loved ones on or after the death of the deceased potential donor¹⁵⁴. Supporters of the opting-out system envisage any objections being recorded on a formal register without any reason being required but, according to the British Medical Association, even a verbal objection should be sufficient¹⁵⁵. Belgium has established a Centralized Registry to record objections from those wishing to opt out from being an organ donor; however, only 1.8 per cent of

¹⁵⁰ The Potential Impact Of An Opt Out System For Organ Donation In The UK, An Independent Report From The Organ Donation Taskforce, article 5.2, p.11

¹⁵¹ *Ibid.*

¹⁵² *Ibid.*, p.23

¹⁵³ For instance, in Belgium the doctors can remove organs from every adult who dies, unless a person has registered to opt out or the person's relatives tell the doctors not to take the organs. It is up to the relatives to tell the doctors because the doctors may not ask them. Comparatively, in Spain, though the doctors can remove organs from every adult who dies and did not register to opt out, it is good practice for doctors there to ask the relatives for their agreement at the time of death. Referred from "*The Potential Impact of an Opt Out System For Organ Donation In The UK, An independent Report From The Organ Donation Taskforce*, p.10, www.dh.gov.uk/organdonationtaskforce, viewed on 6 April 2011.

¹⁵⁴ Shaun D. Pattinson, *Medical Law and Ethics*. (London, Sweet & Maxwell, 2006) p.429.

¹⁵⁵ See BMA 2000, part 2 and 2004, 434 in Shaun D. Pattinson. *Medical Law and Ethics*. (London, Sweet & Maxwell, 2006) p 429.

Belgians have in fact recorded such an objection¹⁵⁶. Nevertheless, this opting-out system is seen as a huge relief for family members, as they are relieved of the burden of having to decide and give consent on whether the deceased's organs should be donated or not¹⁵⁷. This burden can commonly cause familial distress¹⁵⁸ and, even in cases where the decision-making is still available to families, the weight of the decision is made lighter, particularly by knowing that the deceased, during his/her lifetime, had never decided to "opt out" of presumed consent and had agreed to donate his/her organs¹⁵⁹.

The hard opting-out may perhaps be closely related to 'compulsory taking' which resonates with the notion that cadavers belong to the state, and are to be used for valid therapeutic purposes¹⁶⁰, while others regard it as a compulsory act of recycling organs¹⁶¹. However, J. Kevorkian took a stronger, negative stand by observing that the absence of consent is arguably equivalent to an act of stealing (organs) by the state¹⁶². Because there is no actual consent from the individual, as consent is presumed, there is a possibility that the deceased might not have used his/her opportunity to opt out even if he/she had wanted to. So it is possible to argue that there is actually no element of consent existing at all¹⁶³. Here, consent is fictionalized in the absence of any positive indication that organ transplantation and removal has been agreed¹⁶⁴. So, in these situations, rather than relieving grieving relatives of the burden of deciding about donation, it might turn into a morally degrading act which takes away the option of an individual to decide by his/her own consciousness whether or not to donate his/her organs¹⁶⁵. Additionally, this could

¹⁵⁶ David Price. *Legal and Ethical Aspects of Organ Transplantation*, (United Kingdom, Cambridge University Press. 2002) p.91

¹⁵⁷ Kennedy, I, Sells, R.A. Daar, A.S, et al, "The case for 'Presumed Consent'" in Organ Donation, (1998), *The Lancet*, Vol.351,1650-1652

¹⁵⁸ Cohen.C, 'The Case for Presumed Consent to Transplant Human Organs After Death', in David Price, *Organ and Tissue Transplantation* (England, Ashgate Publishing Limited, 2006), p.196

¹⁵⁹ Martine Rothblatt, *Your Life or Mine*, (England, Ashgate Publishing Limited, 2004), p.2

¹⁶⁰ David Price, *Legal and Ethical Aspects of Organ Transplantation*, (United Kingdom, Cambridge University Press, 2002) p.84.

¹⁶¹ *Ibid.*

¹⁶² Kevorkian, J. 'A Controlled Auction Market is a Practical Solution to the Shortage of Transplantable Organs', (1992) 11 *Medicine and Law*, 47.

¹⁶³ Erin C. and Harris, J. 'Presumed Consent or Contracting Out', (1999) 25 *Journal of Medical Ethics*, 365.

¹⁶⁴ *Ibid*

¹⁶⁵ John Fabre, 'Organ Donation and Presumed Consent'. 11 July 1998. *The Lancet*. Vol.352, Issue 9122, p.150

cause ill-will, particularly when the organs had been removed and relatives subsequently came forward with objections¹⁶⁶. Nevertheless, if extensive comprehension and massive campaigns of public education on the matter could be ensured, the concerned parties would have sufficient knowledge about it¹⁶⁷. Meanwhile, whether silence indicates a lack of understanding rather than agreement is another issue that must be considered.

Another negative point about this system is that it allows exposure to more medical risks since the removal of organs is done without prior discussion with relatives. This is actually important because families and relatives may know about the donor's previous medical history and could prevent the harvesting of affected organs¹⁶⁸.

a) Spain

Spain has a “hard” presumed consent law but has never practised it¹⁶⁹. This is why it is more popularly known for applying the ‘soft’ opting-out system where doctors take active measures to ascertain that the families do not object to organ procurement from the deceased¹⁷⁰. Nevertheless, this has still consolidated Spain's position in reaching the world standard in organ donations¹⁷¹ and becoming the country with the highest rate of organ donors in Europe¹⁷². Initially, the organ donation rate in Spain was only 14 per million of population; however, drastic changes were made in 1989¹⁷³ when the National Transplant Organization was founded as a new infrastructure¹⁷⁴. It started to improve its

¹⁶⁶ *Opt in or Opt Out*.

http://www.uktransplant.org.uk/ukt/newsroom/statements_and_stances/statements/opt. viewed on 5 March 2008.

¹⁶⁷ *Ibid.*

¹⁶⁸ *Ibid*

¹⁶⁹ W'odarczyk, Z, ‘Legal Aspects of Organ and Tissue Transplantation’, (2003) 35 *Transplantation Proceedings*, 1202-1203, p.1202

¹⁷⁰ Amber Rithalia, Sara Suekarran, Lindsey Myers and Amanda Sowden, ‘Impact of Presumed Consent for Organ Donation on Donation Rates : A Systematic Review’, (2009) *BMJ* 338:a3162

¹⁷¹ Xavier Bosch, ‘Spain Celebrates Leading World in Organ Donation’, (1998) Vol.351, June 20, *The Lancet*, 1868

¹⁷² Bruno Simini, ‘Tuscany Doubles Organ-Donation Rates by Following Spanish Example’, (2000), Vol. 355, February 5, *The Lancet*, 476.

¹⁷³ House of Lords European Union Committee 17th. Report of Session 2007-08, *Increasing the Supply of Donor Organs Within the European Union*, Volume I: Report, (2008, The Stationary Office Limited, London), para 185, p.39

¹⁷⁴ The Potential Impact Of An Opt Out System For Organ Donation In The UK, An Independent Report From The Organ Donation Taskforce, Article 11.4, p.22

coordination system by providing plenty of support and training to all its transplant coordinators¹⁷⁵, recruiting more estate planners, nurses, emergency and intensive care physicians and upgrading hospital facilities¹⁷⁶. Afterwards, in 1997, Spain's organ donation rate increased to 29 donors per million of population while, in 1998¹⁷⁷, it rose to the rate of 30 donors per million people¹⁷⁸. The following year, its National Transplant Organization released data showing that organ donation in Spain had increased by another 6.7%, achieving 33.6 donors per million of population¹⁷⁹. Recently, in 2007, the donation rate reached 34.4 donors per million of population¹⁸⁰.

The opting-out law in Spain initially considered any person certified brain-dead a potential donor unless he or she had previously expressed denial of such consent¹⁸¹. Later, after an important change was made to update the 1980 legislation, the potential donor pool was extended to include people who die of sudden cardiorespiratory arrest or asystole¹⁸². Therefore, any person judged to be dead "by means of cardiorespiratory criteria", including having unequivocal evidence of absence of both heartbeat and spontaneous breathing for 5 minutes after appropriate resuscitation procedures, will be considered a potential organ donor¹⁸³. Practising a soft opting-out law means that the relatives' views are considered and they can refuse donation even if the deceased wanted to donate his/her organs¹⁸⁴. That is why, in practical terms, the hospital staff members always approach the surviving family members, not to request permission to procure organs, but to ascertain whether they would prefer not to allow procurement to proceed as

¹⁷⁵ Celia Wight and Bernard Cohen, 'Organ Shortages: Maximising the Donor Potential, (1997), *British Medical Bulletin*, 53 (No.4) pg 817

¹⁷⁶ Raymond Pollak, 'Cadaver Donors Are The Best Solution To The Organ Shortage', (2005-2006) 55 *DePaul L.Rev.*, 897

¹⁷⁷ Xavier Bosch, 'Spanish Organ Donation is Increasing', (1999), *The Lancet*, Vol.353, February 6, , 476.

¹⁷⁸ Xavier Bosch, 'Spain Celebrates Leading World in Organ Donation', (1998) *The Lancet*, Vol.351, June 20, 1868

¹⁷⁹ Xavier Bosch, 'Spain Widens Donor Pool by Updating Organ Laws', (2000) *The Lancet* Vol.355, January 15, 212

¹⁸⁰ The Potential Impact Of An Opt Out System For Organ Donation In The UK, An Independent Report From The Organ Donation Taskforce, Article 11.3, p.22

¹⁸¹ Xavier Bosch, 'Spain Widens Donor Pool by Updating Organ Laws', (2000) *The Lancet*, Vol.355, January 15, 212.

¹⁸² *Ibid*

¹⁸³ *Ibid*

¹⁸⁴ Jaish Puri. 'Should Organ Donors be Paid?', (2008) *International Journal of Surgery*, Vol.6. Issue 3, 181-183.

it normally would¹⁸⁵. Spain also approves living organ donations as long as the organ removal is “compatible with life” for the donor. It also introduced a new diagnostic criterion of brain death based on rapid cerebral blood flow measurement where, previously, brain death was diagnosed by having two electroencephalograms, the second being obtained six hours after the first one¹⁸⁶. However, advertising for organ or tissue donation from individuals or health centres is forbidden in Spain, including providing any type of reward or remuneration for any donated organs or tissue¹⁸⁷. This is because Spain still emphasizes that organ donations should be based on voluntary values and the spirit of altruism¹⁸⁸.

b) Austria

Austria has the second-highest organ donation rate per million population after Spain¹⁸⁹ although, contrastingly, it has operated the hard opt-out system ever since 1982¹⁹⁰, and does not take into account the views of those close relatives when harvesting available organs for transplantation purposes¹⁹¹. So, organ transplantation will proceed unless it is known that the deceased objected before death¹⁹², and the views of relatives are not actively sought¹⁹³. Thus, only the views of the deceased are taken into consideration, and whenever the person disagrees with any removal of his/her organs he/she must always carry a written statement to this effect, which is normally enclosed with the identification

¹⁸⁵ Sam Crowe and Eric Cohen. *Organ Transplant Policies and Policy Reform*.

http://www.bioethics.gov/background/organ_recs.html. viewed on 21 October 2009.

¹⁸⁶ Xavier Bosch, ‘Spain Widens Donor Pool by Updating Organ Laws’, (2000) *The Lancet*, Vol.355, January 15, 212.

¹⁸⁷ *Ibid*

¹⁸⁸ *Ibid*

¹⁸⁹ Remco Coppen, Roland D Friele1, Sjeff KM Gevers, Geke A and Jouke van der Zee1, The Impact of Donor Policies in Europe: A Steady Increase, But Not Everywhere, (2008) *BMC Health Services Research*, Vol.8, No.235,

¹⁹⁰ Jaish Kumar Puri, ‘Should Organ Donors Be Paid’, (2008) *International Journal of Surgery*, issue 3, 181-183.

¹⁹¹ WHO, Legislative Responses to Organ Transplantation, (1994, Kluwer Academic Publishers, Dordrecht), pp. 276-280 and Kennedy, I, Sells, A, Daar, AS. et al, “The Case for ‘Presumed Consent’ in Organ Donation, (1998), *The Lancet*, Vol.351, 1650-1652

¹⁹² Marc Stuart, Kay Wheat and John Tingle, Sourcebook on Medical Law, (2002, Cavendish Publishing, Great Britain), p.652

¹⁹³ Amber Rithalia, Sara Suekarran, Lindsey Myers and Amanda Sowden, ‘Impact of Presumed Consent for Organ Donation on Donation Rates : A Systematic Review’, (2009) *BMJ* 338:a3162

card¹⁹⁴. Another possibility is to have one's name recorded in the Opting-Out Register, which is a central index that transplantation surgeons can consult around the clock before removing any organs¹⁹⁵. This system has enabled Austria to claim the highest cadaver kidney donor rate among the leading 'transplant countries'¹⁹⁶ and the country has witnessed a more than doubled donation rate of 4.6 per million people per year (pmp/yr) to 10.1 pmp/yr in 1985¹⁹⁷, only after four years of implementing the hard opting-out system. To this day, Austria continues to have an impressive donation rate¹⁹⁸.

c) Singapore

Singapore introduced opting-out legislation after a long period of transplant activity under an 'opting-in' system initially¹⁹⁹. This change was prompted by Goh Chok Tong, the Health Minister, as a solution to obtain more cadaveric kidneys in 1987²⁰⁰. This Human Organ Transplants Act (HOTA), though applicable throughout the country, initially exempted Muslims and persons over the age of 60. Minors under 21 years of age and persons of unsound mind were also exempted from this system, unless parental consent had been obtained. This Act initially allowed kidney removal for transplantation purposes, following brain death certification, unless any objection had been registered during the lifetime of that individual²⁰¹. These kidneys were mainly harvested from cadaveric donors involved in road traffic accidents; however, any person not willing to donate their kidneys after death could still register their objections²⁰². Success followed

¹⁹⁴ Organ Donation, Austrian Embassy Canberra, <http://www.bmeia.gv/en/embassy/canberra>, viewed on 1 October 2010

¹⁹⁵ *Ibid*

¹⁹⁶ New, B, Solomon, M, Dingwall, R and Mc Hale, J, 'A Question of Give and Take: Supply of Organs for Transplantation', (1994, King's Fund Institute, London), p.35.

¹⁹⁷ Romelie Rieu, 'The Potential Impact of an Opt-Out System for Organ Donation in the UK', (2010) *Journal Medical Ethics*, 36, 534-538.

¹⁹⁸ Statistics from Figure 1, Consent Systems and Donation Rates, 2002 showed approximately 24 people per million population are organ donors in Austria in 2002. *Journal of Health Economics and New Scientist* Copyright New Scientist referred from Romelie Rieu, 'The Potential Impact of an Opt-Out System for Organ Donation in the UK', (2010) *Journal Medical Ethics*, 36, 534-538.

¹⁹⁹ Jean McHale and Marie Fox, *Health Care Law Text and Materials*, (London, Sweet & Maxwell Limited, 2007), p. 1165.

²⁰⁰ Chew, Valarie, 'Human Organ Transplant Act (HOTA), http://infopedia.nl.sg/articles/SIP_1401_2009-01-08.html, Viewed on 20 October 2009.

²⁰¹ Kaur, M. 'Organ Donation and Transplantation in Singapore'. November 1998, *Transplantation Proceedings*. Volume 30, Issue 7, p.3631

²⁰² *Ibid*.

this big change as donor numbers increased from 4.7pmp/yr to 31.3pmp/yr²⁰³, and in 1989-1990 the number of transplants increased significantly, allowing Singapore to discontinue importing kidneys from Europe and North America²⁰⁴. Then, in 2004, the Act included deaths resulting from non-accidental causes as a potential source as well. Compared to the previous 1987 Act which only focused on kidney transplants, the 2004 amendments covered more organs and tissues including livers, corneas and hearts, particularly in cadaveric organ donations²⁰⁵.

Later, in 2008, further amendments took place in the HOTA. This time, the changes sought to include Muslims as potential organ donors as well. Simultaneously, due to certain circumstances, the Singapore Fatwa Committee, made up of eminent religious leaders and chaired by the Mufti of Singapore Mr. Said Isa Mohd. Semait, had reconsidered organ donation matters involving Muslims. Before this, as the HOTA excluded Muslims, those wishing to donate their organs had to register themselves as potential donors upon their death but only 16,000 out of 300,000 Muslims in Singapore had willingly become potential donors, which is not compatible with the demand for organs among Muslims, which is undeniably constantly high²⁰⁶. However, according to Mr. Nazirudin Nasir, Head of Religious Council Singapore (MUIS), the results of a survey conducted among Singaporean Muslims showed that 70 per cent of them were in favour of being included under the HOTA²⁰⁷. Thus, based on historical religious texts and considering contemporary issues and developments in the Islamic world, the Religious Council decided that Singaporean Muslims should also be included under the HOTA to allow more Muslims to benefit from it and to help save more precious lives. However,

²⁰³ Romelie Rieu, 'The Potential Impact of an Opt-Out System for Organ Donation in the UK', (2010) *Journal Medical Ethics*, 36, 534-538.

²⁰⁴ Jean McHale and Marie Fox, *Health Care Law Text and Materials*, (London, Sweet & Maxwell Limited, 2007), p. 1165.

²⁰⁵ Chew, Valarie, 'Human Organ Transplant Act (HOTA)', http://infopedia.nl.sg/articles/SIP_1401_2009-01-08.html, Viewed on 20 October 2009.

²⁰⁶ 'Singapore to Assume All Muslims are Willing Donors'. 27 July 2007. www.uk.reuters.com/article/latestCrisis/idUKSIN2146112007/07/27 viewed on 5 January 2008.

²⁰⁷ Loh Chee Kong, 'A Muslim Rethink on Organ Donation'. 25 July 2007. *Todayonline*. www.todayonline.com/articles/202511.viewed on 5 January 2008.

there had to be assurances that the time needed to remove the organs would be shortened and no delays should take place in the burial process²⁰⁸.

Islamic Law actually requires explicit consent in organ donation procedures but, considering that the response to the pledging scheme is very low and bearing in mind all the difficulties that must be overcome, the opting-out system is now accepted as a form of consent²⁰⁹. Nevertheless, to apply this new fatwa, extensive public education programmes and various other means of outreach must be undertaken to inform the Muslim community about the chance to opt out of the HOTA if they decline to become potential donors in the future.

By virtue of this fatwa, in January 2008, the Singapore Minister of Health finally announced that the HOTA 2004 had been passed by the Parliament to include Singapore Muslims, starting from August 1st 2008, in an effort to enlarge the donor pool²¹⁰, while enhancing the access of Muslims with organ failure to donated organs²¹¹. This new amendment will automatically presume that all Muslims aged between 21 and 60 have agreed to donate vital organs including kidneys, heart, liver and corneas upon death unless they had opted out of the system earlier.

Recently, by virtue of the latest 2009 amendments, starting from 1st November 2009, HOTA will officially cover all Singapore Citizens and Permanent Residents of 21 years and above, who are of sound mind, unless they have opted out. Those aged 60 and above have now officially been excluded from this organ donation system²¹². So, although consent to donate organs is presumed among qualified citizens, there is still space for those who wish to opt out. This ensures that elements of coercion and force do not exist

²⁰⁸ *Ibid.*

²⁰⁹ *Singapore to Assume All Muslims are Willing Donors*, 27 July 2007.

www.uk.reuters.com/article/latestCrisis/idUKSIN2146112007/07/27.viewed on 8 January 2008.

²¹⁰ 'Singapore to Include Muslims in Organ Donation Laws'

<http://afp.google.com/article/ALeqM5jE9aDRRy2qdp65v8wQOBXC56g-pQ>. viewed on 5 March 2008.

²¹¹ 'Singapore Muslims in Donor Ruling' <http://news.bbc.co.uk/2/hi/asia-pacific/6919879.stm>. viewed on 5 March 2008.

²¹² Ministry of Health Singapore, 'Human Organ Transplant Act (HOTA)', Frequently Asked Questions on HOTA, <http://www.pqms.moh.gov.sg/apps/fcd>, viewed on 20 October 2009.

within the system, as citizens wishing to opt out will simply need to fill in a pink “Objection to Organ Removal under Section 9(1)” form, which can also be downloaded from the Ministry of Health’s website, and send it to the National Organ Transplant Unit²¹³. Singaporeans are also still at liberty to choose either to opt out totally from being an organ donor, or to just opt out for specific organs, for example, to donate kidneys but not the liver, cornea and the heart²¹⁴. If a person wishes to opt out, it must be done during his/her lifetime and while he/she is still able to do so, as family members cannot opt out on behalf of another even if that person is in a comatose state. However, once a person chooses to opt out, he/she will consequently get lower priority on the organ transplant waiting list should he/she require an organ transplant in the future²¹⁵. This is similar to the practice applied in Austria, where it is perhaps intended to prevent people from taking advantage of others, particularly by not being willing to become a donor themselves, but at the same time still wanting to enjoy the benefits of the system from others who have agreed to contribute and become organ donors.

However, despite the smoothness of the system, controversies sometimes still occur, creating sensational stories for the media. Consider what happened to Mr. Sim Tee Hua, aged 43, who collapsed at work and was declared brain-dead due to a stroke and brain haemorrhage. Upon confirmation by the hospital of his condition, the hospital staff wanted to proceed with organ-harvesting but his relatives requested a delay of another 24 hours hoping that a miracle would happen and he would wake up. Their request was allowed but, after this period had expired, the family requested another 24 hours, which was rejected since this would have caused the organs to become unusable. The transplant medical team had no choice but to carry on with the operation. The doctors’ acts were justified as, under the HOTA 2004, kidneys, livers, hearts and corneas suitable for transplant can be removed from all Singaporeans and permanent residents who are non-Muslims, upon their death, unless they had opted out from being potential donors. Since Mr. Sim had never opted out, his family was totally powerless to stop his organs from

²¹³ *Ibid*

²¹⁴ *Ibid*

²¹⁵ Ministry of Health Singapore, ‘Human Organ Transplant Act (HOTA)’, Frequently Asked Questions on HOTA, <http://www.pqms.moh.gov.sg/apps/fcd>, viewed on 20 October 2009.

being removed. According to the Ministry of Health, whenever such situations happen the doctors will try to accommodate the family's request but, at the same time, they also need to consider the time factor which will affect the condition of the organs being harvested²¹⁶. However, some still felt that compassion and humanity should always prevail in such situations, where the family is still reeling from shock over the death of a loved one²¹⁷. This incident indirectly shows that many people are still unaware that certain organs can be taken away upon their death unless they have chosen to opt out earlier. The Singapore Ministry of Health was criticized and urged to ensure that this system is publicized and understood by the Singaporeans while simultaneously making all the opt-out forms more readily available, including online, so that people need not go hunting for these forms in clinics and hospitals²¹⁸.

However, although a few countries such as Singapore and Austria have recorded an increase in donation rates of up to 25%²¹⁹, it must be remembered that this was not achieved by the change in legislation alone²²⁰. Each country introduced many other changes at the time of the legislation including improved infrastructure, increased funding for transplant programmes and increased awareness among society²²¹. Moreover, not all countries switching to the opting-out system have high organ donor rates. For example, Sweden applied the opting-out system in 1996, but continues to be among those with the lowest organ donation rates in Europe²²². This is possibly due to the success of policies on CVA treatment and traffic safety since there is a strong correlation between mortality rates from Cerebral Vascular Accidents (CVA) and traffic accidents and

²¹⁶ Tracy Sua, 'Brain-Dead Man's Kin in Scuffle over Op to Remove Organs'. *The Straits Time Online*. 8 February 2007, viewed on 5 January 2008.

²¹⁷ Lim Boon Hee. SGH Could Have Handled Removal of Organs Better. *Straits Times Forum Online*. 10 February 2007, viewed on 5 January 2008.

²¹⁸ *Ibid*

²¹⁹ The Potential Impact of an Opt Out System for Organ Donation in the UK, an Independent Report from the Organ Donation Taskforce, p.22

²²⁰ Shaun D. Pattinson, *Medical Law and Ethics*, (London, Sweet & Maxwell, 2006), p.430.

²²¹ The Potential Impact of an Opt Out System for Organ Donation in the UK, an Independent Report from the Organ Donation Taskforce, p.22

²²² The Potential Impact of an Opt Out System for Organ Donation in The UK, An Independent Report from the Organ Donation Taskforce, p.22

donation rates²²³. Brazil (which adopted the ‘hard’ presumed consent law) and France also experienced a negative impact from the presumed consent system, due to claims of mistrust of the government, including accusations of body snatching, which damaged the public trust respectively²²⁴. This shows that a presumed consent system alone does not necessarily guarantee higher donation rates and that changing the consent system does not have a significant impact on the trends of donor efficiency rates²²⁵.

2.3 THE CONSCRIPTION SYSTEM

A conscription system is one where tissue and organs can be removed posthumously for transplantation, irrespective of any consent or refusal²²⁶. Under this system, dead bodies or their parts are treated as public property either indefinitely or for a limited period before what remains is released for disposal²²⁷. This means that organs from cadavers can be harvested automatically and be made mandatorily available as neither the relatives nor former ‘owners’ of the cadavers need to be consulted about their organ disposal²²⁸. As this system removes the necessity to seek permission at a grieving moment of death while also removing any moral objections to it²²⁹, it holds that neither the deceased nor their surviving loved ones have any relevant moral interest in controlling what happens to the tissue and organs or that their moral interests are overridden by positive duties and sacrifice towards the community, to the extent of denying autonomy and violating bodily integrity²³⁰. A strict system of conscription would supposedly maximize the supply of cadaveric organs for transplantation²³¹ while avoiding the complexity of having reluctant

²²³ Remco Coppen, Ronald D Friele, Sjeff KM Gevers, Geke A Blok and Jouke van der Zee, The Impact of Donor Policies in Europe: A Steady Increase, But Not Everywhere, *BMC Health Services Research*, (2008) 8, 235

²²⁴ The Potential Impact of an Opt Out System for Organ Donation in The UK, An Independent Report from the Organ Donation Taskforce, p.23

²²⁵ Romelie Rieu, ‘The Potential Impact of an Opt-Out System for Organ Donation in the UK’, (2010) *Journal Medical Ethics*, 36, 534-538.

²²⁶ Shaun D. Pattinson, *Medical Law and Ethics*, (London, Sweet & Maxwell, 2006) p.429.

²²⁷ *Ibid*

²²⁸ John Harris, ‘Organ Procurement: Dead Interests Living Needs’, (2003) 29 *J.Med.Ethics*, 130-134

²²⁹ *Ibid*

²³⁰ *Ibid*

²³¹ Shaun D. Pattinson, *Medical Law and Ethics*, (London, Sweet & Maxwell, 2006), p.419.

staff members confront families, asking for consent to procure organs²³². The only major concern about conscription is that it violates autonomy²³³, though this might be better tolerated than allowing more people to die for lack of organs for transplantations²³⁴. Moreover, there is a controversial view that the cadaver has no autonomy: thus it cannot be harmed nor suffer pain²³⁵.

a) China

In organ conscription, governments can simply harvest organs from potential donors²³⁶. China stands alone in continuing to use the organs of executed prisoners for transplant surgery²³⁷ though some Western countries, particularly France²³⁸ and the USA²³⁹, also applied this policy in the earlier days of organ transplantation activities. China implemented a policy of organ conscription which has routinely harvested organs from prisoners since 1983. This policy was known as the “Strike Hard” campaign which announced that China would begin executing common criminals, and the death penalty is considered legal²⁴⁰. However, compared to other countries, which support capital punishments for only the worst crimes, China classifies more than 68 offences as capital, including car theft, embezzlement and discharging of a firearm²⁴¹. This explains why, each year, the number of executions in China exceeds by at least twofold the number of executions in the rest of the world put together²⁴². In 1984, the Chinese government issued a policy paper entitled Provisional Regulations [...] on the Use of Dead Bodies or

²³² Spital, A, ‘Conscription of Cadaveric Organs for Transplantation: Time to Start’, (2006) 70 *Kidney International*, 607

²³³ *Ibid*

²³⁴ Jonsen AR, ‘Transplantation of Fetal Tissue : An Ethicist’s Viewpoint’, (1988) 36 *Clin Res*, 215-219

²³⁵ *Ibid*

²³⁶ Amitai Etzioni, ‘Organ Donation : A Communitarian Approach’, (2003) *Kennedy Institute of Ethics Journal*, Vol.13, No.1, 1-18, p.2

²³⁷ Thomas Diflo, ‘Use of Organs from Executed Chinese Prisoners’, (2004) *The Lancet*, Vol.364, December, pp.30-31.

²³⁸ Francois Mosimann, ‘Procurement of Organs from Executed Prisoners’, (2005) *The Lancet*, Vol.365, March 5, pp.843-844.

²³⁹ Meredith JH, ‘Organ Procurement from the Executed’, (1986) 18 *Transplant Proceedings*, pp.406-407.

²⁴⁰ Burns, John P, ‘When Peking Fights Crime, News in On The Wall’, (1986) *New York Times*, 135, Jan 2S, 6, A2, in Carl Becker, ‘Money Talks, Money Kills—The Economics of Transplantation in Japan and China’ (1999) *Bioethics*, Vol. 13, No. 3/4, 236-243, p.239

²⁴¹ Thomas Diflo, ‘Use of Organs from Executed Chinese Prisoners’, (2004), *The Lancet* Vol.364, December, pp.30-31.

²⁴² *Ibid*

Organs from Condemned Criminals, which stipulated that the prisoners were to be executed by being shot²⁴³. Following that, China then created “Rules Concerning the Utilization of Corpses or Organs from Corpses of Executed Criminals”²⁴⁴. This law allows the government to use a prisoner’s organs if that prisoner consents to donate²⁴⁵, or the prisoner’s family have consented, or in a situation where nobody claims or collects the body^{246,247}. These rules are believed to actually assure consent, regardless of the actual desire of the prisoner or his family²⁴⁸. Moreover, prisoners are commonly abandoned by their families due to shame or fear of repercussions²⁴⁹. At a World Health Organization meeting in November 2005, the vice-minister of China’s Ministry of Health disclosed that 95% of organs transplanted in hospitals in China come from executed criminals, with the other 5% coming from living donors²⁵⁰. In 2005, reports by human rights group Amnesty International observed that at least 1,770 people had been executed, although the true figure is believed to be much higher²⁵¹. Every year, thousands of prisoners are executed to provide fresh organs for transplantation in times and places where they are most needed²⁵². These prisoners are shot through the back of their heads, drugged, intravenously and occasionally respirated, so that their hearts will keep beating until they are transplanted to the recipient²⁵³. Their organs are sold to high-paying

²⁴³ *Ibid*

²⁴⁴ The Bellagio Task Force Report on Transplantation, Bodily Integrity, and the International Traffic in Organs, (1997) 29 *Transplant Proceeding* 2739-2749

²⁴⁵ Carl Becker, ‘Money Talks, Money Kills—The Economics of Transplantation in Japan and China’ (1999) *Bioethics*, Vol. 13, No. 3/4, 236-243

²⁴⁶ *Illegal Human Organ Trade from Executed Prisoners in China*.

<http://www.american.edu/TED/prisonorgans.htm>. viewed on 5 March 2008.

²⁴⁷ Laura-Hill M. Patton, ‘A Call For Common Sense: Organ Donation and the Executed Prisoner,’ 34 *St. Mary’s L.J.* 687-732, p.698

²⁴⁸ Thomas Diflo, ‘Use of Organs from Executed Chinese Prisoners’, (2004) *The Lancet* Vol.364, December, pp.30-31.

²⁴⁹ *Ibid*

²⁵⁰ ‘Human Rights in China’ 19 April 2006, *Congressional Quarterly*, and ‘A Harvest of Horrors’ 22 May 2006, *Western Standard*, cited from Sam Crowe and Eric Cohen. *Organ Transplant Policies and Policy Reforms*. www.bioethics.gov/background/crowepaper.htm. viewed on 12 January 2008.

²⁵¹ *Organ Sales ‘Thriving’ in China*.

<http://news.vote.bbc.co.uk/mpapps/pagetools/print/news.bbc.co.uk/1/hi/world/asia-pac>. viewed on 5 March 2008.

²⁵² Carl Becker, ‘Money Talks, Money Kills—The Economics of Transplantation in Japan and China’ (1999) *Bioethics*, Vol. 13, No. 3/4, 236-241

²⁵³ *Ibid*

foreigners needing transplants, and livers are reported to cost £50,000 each²⁵⁴. So, although it is often reported that these organs are taken with the express permission of the convict²⁵⁵, there are still many assertions that Chinese medical staff immediately procure organs from executed prisoners without the prior consent of the prisoner or his family²⁵⁶. And, as the brain death concept is not well-defined or fully accepted in China, it is even possible for organs to be procured from prisoners who are not brain dead²⁵⁷. This was alarming and consequently raised doubts about whether the prisoners who surrendered their organs had actually acted freely. Recently, however, China's Ministry of Health and the Red Cross Society of China have jointly launched a pilot organ donation system in five cities and provinces, including cities such as Nanjing, Shanghai, Tianjin, Wuhan and Xiamen and the provinces of Guangdong, Jiangxi, Liaoning, Shandong and Zhejiang, to harvest organs from confirmed brain stem-dead patients as part of China's initiative to come into line with internationally accepted practices in organ donation²⁵⁸.

The Chinese Medical Association had announced an agreement, in 2007, to restrict the use of organs from executed prisoners for donation to immediate relatives²⁵⁹, thus curbing transplant tourism and also organ trafficking²⁶⁰. However, despite such announcements, its military hospitals are reported to have disregarded the ban and are still selling organs from executed prisoners, although its Ministry of Health denies it²⁶¹. Their long-term goal is to abolish the death penalty but, until this takes place, certain regulations have been established to protect prisoners' rights and desires and to separate

²⁵⁴ Organ Sales 'Thriving' in China.

<http://news.bbc.co.uk/1/hi/world/asia-pac>. viewed on 5 March 2008.

²⁵⁵ *Ibid*

²⁵⁶ Allison K. Owen, 'Comment, Death Row Inmates or Organ Donors : China's Source of Body Organs For Medical Transplantation', (1995) 5 *Ind. Int'l & Comp. L. Rev* 495 in Donny J. Perales, 'Rethinking The Prohibition of Death Row Prisoners As Organ Donors : A Possible Lifeline To Those On Organ Donor Waiting Lists', (2002-2003) 34 *St. Mary's L.J.* 687-732, p.698

²⁵⁷ Thomas Diflo, 'Use of Organs from Executed Chinese Prisoners', (2004) *The Lancet* Vol.364, December, pp.30-31.

²⁵⁸ Jane Parry, 'China Starts to Move Away from Using Organs from Executed Prisoners for Transplantations', (2009) *BMJ*, 2 September, 339:b3567.

²⁵⁹ *Ibid*.

²⁶⁰ Millis, J.M, Huang, J, Millis, M.A, et al, '2007 : The Year of Regulatory Change', (2009) 41 *Transplantation Proceedings*, 25-26, p.26

²⁶¹ Sue Pondrom, 'Transplant Leaders Take On Organ Trafficking', *The ATJ Report, News and Issues That Affect Organ And Tissue Transplantation*, (2008) 8 *American Journal of Transplantation*, 1571-1572

transplant programmes from the prison system²⁶². China has set up additional safeguards to ensure these rights by requiring written consent for organ removal from the prison donor, reviewing all death sentences by the Supreme People's Court; and limiting every transplant professional's involvement only until death has been officially declared²⁶³.

2.4 ORGAN TRADING

There are limits to what can be bought or sold as commodities as some things are so valuable, priceless or sacred that they should never be allowed into the marketplace²⁶⁴. This includes human organs, the buying and selling of which is widely considered to be morally pernicious²⁶⁵. An organ donor can donate a body or its organs to benefit a country or society, but not for private profit²⁶⁶. Allowing the organ market can be perceived by some as showing disrespect to one's body parts²⁶⁷ while treating them no differently from any other goods offered for sale. For example, in 1999, the media reported on a man from Florida who had auctioned a kidney on e-bay. It managed to reach a bid price of 5.7 million dollars, just before the transaction was cancelled by the organisers for reasons of immorality²⁶⁸. In other instances, The World Health Organisation (WHO) reported that illegal organ traffickers charge wealthy clients up to \$100,000 or \$200,000 for an organ²⁶⁹.

The market in body parts, particularly kidneys, has flourished and some patients are travelling with their surgeons to countries where "donated" organs may be purchased legally or illegally²⁷⁰. This increasing demand for organs has also witnessed people willing to pay large amounts of money for their required organs, middlemen touting for

²⁶² Jiefu Huang, Yilei Mao and J Michael Millis, 'Government Policy and Organ Transplantation in China', (2008) *The Lancet*, Vol.372, December 6, 1937-1938.

²⁶³ *Ibid*

²⁶⁴ de Castro, L.D, 'Commodification and Exploitation : Arguments in Favour of Compensated Organ Donation', (2003) 29 *J.Med Ethics*, 142-146, p.142

²⁶⁵ Shaun D. Pattinson, *Medical Law and Ethics* (London, Sweet & Maxwell, 2006) p.419.

²⁶⁶ Orit Braver Ben-David and Aref Abu-Rabia, 'The Experiences of Islamic Minorities in Non-Islamic States', (2002) 21 *Medicine and Law*, 281

²⁶⁷ Jonathan Herring, *Medical Law and Ethics*.(United States, Oxford University Press. 2006) pp.388-390

²⁶⁸ Grace Bradbury, 'Online Bidders' Stake in Kidney', *The Times*, 4 September 1999

²⁶⁹ *Ibid*.

²⁷⁰ Parturkar D, 'Legal And Ethical Issues In Human Organ Transplantation', (2006), 25 *Medicine And Law*, 389

potential donors and organ-trafficking becoming a major problem²⁷¹. This indirectly shows how the selling of organs could spoil the spirit of donating charitably and altruistically. Moreover, the element of consent from the donor might be lacking, as bargained organs are sometimes given under financial duress and will indirectly result in loss of human dignity and social solidarity²⁷². That is why, to this day, organ trading has not been practised openly, although black markets for it do exist.

Black markets involve a high level of risk to both the organ donor and recipient, especially when the transplants are performed under suboptimal conditions and inferior medical scrutiny, involving donors with dubious backgrounds. The recipient additionally bears the risk of receiving an improperly screened organ which might have been infected with certain diseases like HIV, fungi and hepatitis viruses which could cause a high level of short-term mortality²⁷³. Black markets which sell organs contribute to the distribution of contaminated organs, increase the risk of certain contagious diseases and make the risk of death more likely. Putting a price on human organs will also encourage almost anybody, including drug addicts, alcoholics, and carriers of infectious diseases such as hepatitis, HIV and AIDS to sell their organs for money. Moreover, there is a belief that altruistic donors would provide better-quality organs²⁷⁴. Even worse, this could tempt irresponsible people to kidnap and kill others to harvest their organs and make a profit. In Peru recently, three men were arrested in the jungle of Huanuco province for offences of kidnapping and murder. This gang had been committing these crimes for nearly 30 years, to extract human fat from their victims, which was then sold to cosmetic and pharmaceutical companies in Europe for \$15,000 (more than £9000) per litre²⁷⁵. Although human fat does not fall within the definition of tissues or organs and there is no great demand for it, there is still a high value placed on it. So, how much higher would the price be if it involved selling human organs and tissues which are so scarce?

²⁷¹ *Ibid*

²⁷² Martine Rothblatt, *Your Life or Mine* (England, Ashgate Publishing Limited, 2004) p.17

²⁷³ Salahudeen, AK, Woods, HF, Pingle, A, et al. 'High Mortality Among Recipients of Bought Living Unrelated Donor Kidneys'. (1990) *Lancet* 336:725-728[CrossRef][ISI][Medline]

²⁷⁴ Shaun D. Pattinson, *Medical Law and Ethics* (London, Sweet & Maxwell, 2006) p.456

²⁷⁵ 'Gang Held Over Human Body Fat', 20 November 2009, Sky News 2009, www.yahoo.com, viewed on 20 November 2009

Allowing organ-trading will also lead to a situation where wealthy people might take advantage of those who are in urgent need of financial assistance. Donors who are under economic pressure are likely to come from underdeveloped countries; they would be poor, uneducated and ignorant, making their position even more vulnerable²⁷⁶. For example, in India, according to critics, most of the kidneys sold are not expressions of individual autonomy but rather acts of desperation by impoverished individuals²⁷⁷. Therefore, it is undeniable that rich people are the ones benefiting the most, by purchasing the needed organs and evading the law by travelling abroad for transplantation²⁷⁸. However, to assume all organ sales are exploitative would be unfair because, in some cases, the seller could also be a wealthy, consenting, educated, rational and well-informed person, who was paid a very high price²⁷⁹. Here, no elements of coercion or manipulation would become an issue. Nevertheless, one way to combat wrongful exploitation of the poor is by regulating the sale of organs through a governmental organization such as the Human Tissue Authority, at least on an experimental basis²⁸⁰. However, cross-border trade should be prohibited to avoid exploitation of low-income countries²⁸¹, though there are also wide possibilities that elements of nepotism, cronyism, corruption and inertia could get involved²⁸². People in the medical profession would also need to be extra-careful if organ-trading were legalized, as they are more vulnerable to accusations of profiting from the removal of organs from their dying patients; this could generally undermine the ethical aspect of the medical profession²⁸³. In the UK, section 32 of the Human Tissue Act 2004 clearly prohibits any commercial dealings in human organs. The 2004 Act also extends the prohibition to ‘controlled material’ which is defined as all human material intended to be

²⁷⁶ Navqi A. and Rizvi A, ‘Against Paid Organ Donation’, (2001) 33 *Transplantation Proceedings*, 2628

²⁷⁷ Cohen, L, ‘Where it Hurts: Indian Material For An Ethics of Organ Transplantation’, (1999) *Daedalus*, 128, pp135-165 cited in Madhav Goyal, Ravindra, L, Lawrence, J, and Ashwini, R, Sehgal, ‘Economic and Health Consequences of Selling a Kidney in India’, (2002), October 2, *JAMA*, Vol 288, No.13

²⁷⁸ ‘Attempts to Pass Opt Out (Presumed Consent) Legislation in the UK’ . *Bmj.com.Rapid Responses* www.bmj.com/cgi/eletters/3374/7592/502 , viewed on 17 December 2007.

²⁷⁹ Stephen Wilkinson and Eve Garrard, ‘Bodily Integrity and The Sale of Human Organs’, (1996), *Journal of Medical Ethics*, 22, pp.334-339

²⁸⁰ Ahmad, R., ‘Thinking the Unthinkable: Selling Kidneys’, (2006) Web BMJ <http://bmj.bmjournals.com/cgi/eletters/333/7559/149>, viewed on 7 July 2008

²⁸¹ *Ibid*

²⁸² Navqi A. and Rizvi A, ‘Against Paid Organ Donation’, (2001) 33 *Transplantation Proceedings*, 2628

²⁸³ *Ibid*

used for transplantation. However, the prohibitions do not apply to reimbursements for expenses or loss of earnings²⁸⁴.

Looking at the issue from another perspective, there might also be positive impacts from a legal organ market. For Wilkinson and Garrard, this would generate an increased supply of vital organs and provide some much-needed income for those who have little else to sell²⁸⁵. This argument is in line with the libertarians' policy that supports the notion that people should be allowed to dispose of their own body parts in whatever way they wish, which is actually part of their right to autonomy²⁸⁶. So, the legalisation of organ-trading would give everybody the right to decide what is best for them. However, payment given to the living organ owner must be fair compensation, which covers pain, medical care, time and reimbursement of reasonable costs incurred by the donor, especially after the operation. It is also hoped that this would suppress the black market in organs, since donors would now be receiving a fair price and both parties' health needs would be protected²⁸⁷. As for payment to cadaver donors who cannot receive payment in return for their organs, Caplan suggests that such payment should go to a nominated individual or relatives after the donation takes place, which could then be used as financial assistance for funeral expenses. If the payment were to be given immediately after an agreement is reached, it might be slightly risky for the buyer since the seller could still change their mind after receiving the money paid for that particular purpose²⁸⁸. Michele Goodwin proposed a market model that would be restricted to posthumous harvesting only, which would allow the selling of organs from deceased persons only. According to her, this restriction would help avoid murky and problematic issues involving living donations. Under this proposed model, individuals would not be compensated for providing a live donation. Rather, negotiations to transfer organs would

²⁸⁴ Section 32(7) Human Tissue Act 2004 (UK).

²⁸⁵ Stephen Wilkinson and Eve Garrard, 'Bodily Integrity and The Sale of Human Organs', (1996), *Journal of Medical Ethics*, 22, pp.334-339

²⁸⁶ Jonathan Herring, *Medical Law and Ethics*, (Oxford University Press, Oxford, 2006), p.390

²⁸⁷ *Ibid.*, p.391

²⁸⁸ Al Caplan. 'Am I My Brother's Keeper?' *The Ethical Frontiers of Biomedicine* (Indiana UP 1997) 96-98, cited from Emily Jackson, *Medical Law Text, Cases and Material*, (United States, Oxford, 2006) p.724.

only take place upon death. Family members or a decedent's estate, as well as charitable organisations, could be compensated for organ donations²⁸⁹.

a) Iran

Iran's Organ Transplantation Act was passed in the year 2000 after an earlier attempt failed in 1996²⁹⁰; among other things, it officially and totally prohibited the selling and buying of any human organs²⁹¹. Earlier, in 1988, when Iran first introduced its controlled living unrelated renal transplantation program, compensation for donors was provided through appropriate regulated systems, under supervision of ethical authorities, in order to prevent the emergence of illegal markets²⁹². This compensated donation scheme also enabled the authorities to monitor developments and react efficiently, to prevent indecent price escalation that put organ donors at the mercy of affluent buyers²⁹³. Later, in 2006, Iran officially regulated legislation permitting transparent, non-commercial, middleman-free kidney transplantation to take place. Generally, donors are seen as vendors and receive monetary compensation for their body parts, which are not in any way equivalent to payment for their organs²⁹⁴. The Charity Association for the Support of Kidney Patients and the Charity Foundation for Special Diseases are the two non-governmental organizations that organize and monitor this practice. They match donors to recipients²⁹⁵ and, on behalf of the government, reimburse donors with a reward via the charity organisations²⁹⁶ with an amount equivalent to 900 euros each²⁹⁷. This system is

²⁸⁹ Goodwin, Michele. *Black Markets The Supply and Demand of Body Parts*. (The United States of America, Cambridge University Press, 2006) p.22.

²⁹⁰ Bagheri, A, 'Organ Transplantation Laws in Asian Countries: A Comparative Study' (December 2005) *Transplantation Proceedings*. Volume 37, Issue 10, pp. 4159-4162.

²⁹¹ *Organ Transplantation from Cadaver, Law and Regulations in Iran* (2nd. Edition). Management Centre for Transplantation and Special Diseases. Tehran, Iran. <http://www.Irantransplant.org>. viewed on 8 January 2008.

²⁹² Bagher Larijani and Farzaneh Zahedi. *BMJ*, (17 April 2007) *Looking for a Medically Justified Model for Organ Transplantation*, <http://www.bmj.com/cgi/eletters/334/7592/502>, viewed on 24 November 2009

²⁹³ de Castro LD, 'Commodification and Exploitation: Arguments in Favour of Compensated Organ Donation' (2003), 29 *Journal Medical Ethics*, 142

²⁹⁴ Ahad J. Ghods and Shekoufen Savaj. 'Iranian Model of Paid and Regulated Living-Unrelated Kidney Donation'. (2006) 1 *Clinical Journal American Society of Nephrology*, 1136-1145

²⁹⁵ Alireza Bagheri, *A Cross-Cultural Introduction to Bioethics*, (2005) pg. 165

²⁹⁶ Larijani, B, Zahedi, F and Ghafouri, S-Fard, 'Rewarded Gift for Living Renal Donors', (2004) 36 *Transplantation Proceedings*, 2539-2542

considered fair because one party is totally willing to give his kidney, while the other party is totally willing to take it for the price stated. Thus, a satisfactory situation emerges for both parties, although it has not been extended to other organs, except kidneys²⁹⁸. The fixed value would ideally compensate the donor and, at the same time, would not burden the recipient. Besides that, live donors also receive compensation for loss of wages and are granted tax exemption for 2 to 4 years, all of which is regulated under a controlled system by the government.²⁹⁹.

The “Iranian Network for Transplant Organ Procurement” also emphasizes the importance of a complete health assessment, informed consent and follow-up visits for donors; meeting hospital charges, paying a gift of reward and making arrangements for health insurance for living donors are some of the approaches that have been carried out by the “Management Centre for Transplantation and Special Diseases (MCTSD)” of the Ministry of Health in recent years³⁰⁰. So, prior to any donation, donors will be fully examined and checked by a nephrologist and, if there are any health concerns, the proposed donation will be rejected and the recipient will get another matched donor³⁰¹.

The system worked out well, to the extent that some claimed that it had successfully eliminated the waiting list, although this view is indeed controversial and debatable³⁰². The Iranian model managed to prevent exploitation of donors and delivered a good standard of medical service, prompting Dr. Richard Fine, President of the American Society of Transplantation, to recommend the re-evaluation of prohibition of financial incentives for both live donors and the families of deceased donors and advocate that

²⁹⁷ Monir Sadat Hakemi, ‘Kidney on Demand in Iran, Clarification of Some Points’, *BMJ*, (15 March 2007) <http://www.bmj.com/cgi/eletters/334/7592/502>, Rapid Responses to: Anne Griffin, Kidneys on Demand, (2007) *BMJ* 2007; 334: 502-505 viewed on 24 November 2009

²⁹⁸ *Ibid.*

²⁹⁹ Abouna, G.M, ‘Organ Shortage Crisis: Problems and Possible Solutions’ (2008) 40 *Transplantation Proceedings*. 34-38.

³⁰⁰ Bagher Larijani and Farzaneh Zahedi, *BMJ* (17 April 2007) *Looking for a Medically Justified Model for Organ Transplantation*, <http://www.bmj.com/cgi/eletters/334/7592/502>, viewed on 24 November 2009

³⁰¹ *Ibid*

³⁰² Daar, A.S, ‘The Case for a Regulated System of Kidney Sales’, (2006) , *Nat Clin Pract Nephrol*, 2(11), 600-601

long-term donors be given lifetime insurance coverage for any related medical issue³⁰³. Most important of all, the Iranian model upholds the Islamic ruling which prohibits the buying and selling of organs, though the concept of compensated donation is acceptable. However, there are also arguments that such practice is actually similar to legalising the act of buying and selling organs³⁰⁴, and that the monetary incentives paid to the donors by the government are actually misused by the poor³⁰⁵. Moreover, due to the fact that Iran has an inflation rate exceeding 25% and has major problems with unemployment and poverty, it is suspected that people of low socioeconomic class are trading in their kidneys just to fulfill their financial needs³⁰⁶. The rewarding gift given by the government makes it more like a business, where the seller feels deeply dissatisfied as soon as the money is spent³⁰⁷. However, this argument is refuted by Iran as it claims that this is not organ-trading but is actually compensated donation. In every organ donation procedure, all parties involved are benefited either in money or in kind. For example, the organ recipient in particular receives great benefit by obtaining the needed organ, and the medical team, surgeon and transplant coordinator are paid for their services; the organ donor, on the other hand, seems to be the only losing party as he/she is exposed to considerable pain and injury following the operation and has no right to any reward. He/she is also exposed to financial risks, through temporary disability and loss of work³⁰⁸. Therefore, it seems fair to allow donors some form of compensation, which could help ease their burden and worries. Nevertheless, this system, which is limited to transplantations from Iranian donors to Iranian recipients, does not extend to foreigners wanting to buy kidneys in Iran.

³⁰³ Warren, J, 'Time Has Come to Cease Being "Pious About Equity" in Organ Acquisition' (2006) 16 *Transplant News*, 17

³⁰⁴ Daar, A.S, 'The Case for a Regulated System of Kidney Sales', (2006) , *Nat Clin Pract Nephrol*, 2(11), 600-601

³⁰⁵ Mahdanian, A, 'Iranian Model of Living, Non-Related Kidney Donation : A Style To Be Condemned Ethically', (2008) 34 *Medical Humanities*, 120

³⁰⁶ *Ibid*

³⁰⁷ Ghods A.J and Savaj S, 'Iranian Model of Paid and Regulated Living-Unrelated Kidney Donation', (2006) 1 *Clin J Am Soc Nephrol*, 1136-1145

³⁰⁸ Wolters, HH, Heidenreich S, Senninger N, 'Living Donor Kidney Transplantation: Chance for the Recipient-Financial Risk for the Donor?', (2003) *Transplantation Proceedings*, 35, 2091

b) India

India was once considered the hub for commercial transplants in the late 1980s; this brought it worldwide popularity and a lot of media criticism. It had a combination of factors such as trained transplant personnel and a large, impoverished population, but it did not have specific laws regulating organ transplantation activities, thus making it the perfect destination for commercial transplants³⁰⁹. However, after receiving massive criticism, an Act was passed by the Indian Parliament known as Transplantation of Human Organ (THO) Act 1994³¹⁰. This Act banned any payment for organ donation³¹¹. However, in reality, this practice has continued and remunerated transplants are still being performed in several parts of the country³¹², making India known for its thriving black market in organ trading³¹³. A study conducted on 305 living kidney donors in Chennai (Madras) revealed that nearly all of the participants had sold one of their kidneys for financial reasons with 96% paying off debts, 3% providing dowries and expenses for their daughters' marriages and another 1% obtaining cash to start a business³¹⁴. However, they received an average payment of only \$1070 (£638; 1090 euros), a third lower than the average amount promised, and 74% of them were still left with their existing debts³¹⁵. These kidney donors are not only exploited and deprived of any long-term economic benefit but are also believed to suffer from a decline in their health status³¹⁶, as complaints of persistent pain from the scar are very common among them³¹⁷.

³⁰⁹ Vivekanand Jha. 'Paid Transplants in India: The Grim Reality'. *Oxford Journals Medicine Nephrology Dialysis Transplantation*. Volume 19, Number 3. pp541-543.

³¹⁰ Gazette of India 4 February 1995

³¹¹ P.Singh, A.Srivastava, and A.Kumar, 'Current Status of Transplant Coordination and Organ Donation in India', (1998) *Transplantation Proceedings*, 30, 3627-3628

³¹² Vivekanand Jha. 'Paid Transplants in India: The Grim Reality'. *Oxford Journals Medicine Nephrology Dialysis Transplantation*. Volume 19, Number 3. pp541-543.

³¹³ Deborah Josefson, 'Selling a Kidney Fails to Rescue Indians from Poverty', *BMJ*, (2002) 12 October, 325 (7368) 795

³¹⁴ *Ibid*

³¹⁵ *Ibid*

³¹⁶ Madhav Goyal, Ravindra,L, Lawrence, J. Schneiderman, Ashwini,R.Seghal, 'Economic and Health Consequences of Selling a Kidney in India', *The Journal of American Medical Association*, (2002) 288 (13), 1589-1593.

³¹⁷ Saran,R, Marshall, SM, Madson,R, Keavey,P, Tapson,JS, 'Long Term Follow Up of Kidney Donor: A Longitudinal Study', *Nephrol Dial Transplant*, (1997) 12, 1615-1621

2.5 THE REQUIRED REQUEST SYSTEM

This policy of required request is also known as required referral. In this system, enquiries are made to the families of potential donors to see whether they would allow their relatives' organs to be used³¹⁸. In the United States generally, (the specific application in its various states are discussed later) healthcare professionals have a legal duty to enquire into the wishes of the deceased or obtain their surviving loved ones' permission to remove viable organs from a recently deceased potential organ donor³¹⁹. It shall be illegal, irresponsible and immoral to disconnect a ventilator from an individual who is declared dead following brainstem-testing without first making proper enquiries into the possibility of using that individual's tissues and organs for transplantation purposes³²⁰. This system was introduced to prevent and limit the waste of cadaveric organs due to a failure to ask for permission. This system ensures that families are approached for their agreement to organ donation, so that potentially viable organs are not missed³²¹. However, although healthcare professionals are obliged to adhere to this requirement, exceptions known as 'professional privilege' can still apply; in these circumstances they would be exempted from requesting the organs if, by doing so, severe psychological harm might be caused³²². With the application of this system, opportunities for donation are less likely to be overlooked as the next of kin also has a moral and legal right to know that they can donate organs and tissues if they or the family wishes to. This system also standardizes enquiry and places less strain on healthcare professionals and family members while preserving the rights of the individual to withhold consent, since voluntary choice is maintained as its ethical foundation³²³. There are two main features of this system³²⁴. First, the 'Required Request' laws require documentation of the death

³¹⁸ New, B, Solomon, M, Dingwall, R, and McHale, J, *A Question of Give and Take: Improving the Supply of Donor Organs For Transplantation*, London: King's Fund Institute, 1994

³¹⁹ Thomas D. Harter, 'Overcoming The Organ Shortage : Failing Means and Radical Reform', (2008) HEC Forum 20 (2), 155-182, p.155

³²⁰ Opt In or Opt Out. http://uktransplant.org.uk/ukt/newsroom/statements_andstances/statements/opt. viewed on 5 March 2008.

³²¹ Sheila A.M. McLean and Laura Williamson, *Xenotransplantation Law And Ethics*, (Ashgate Publishing Limited, Aldershot, 2005), p.35

³²² Shaun D. Pattinson, 'Medical Law and Ethics', (Sweet & Maxwell, London, 2006), p.432

³²³ Jean McHale and Marie Fox, *Health Care Law*, 2nd ed. (Sweet & Maxwell, London, 2007), p.1169

³²⁴ David Price, *Legal And Ethical Aspects of Organ Transplantation*, (Cambridge University Press, Cambridge, 2000), pp.102-105

certificate with the request made and its outcome; secondly, the ‘Routine Enquiry’ laws require hospitals to develop policies or protocols to ensure that the deceased persons’ families are asked to donate³²⁵.

a) The United States

The required request system has been widely implemented in The United States³²⁶, with a majority of states passing laws incorporating either the ‘Required Request’ law or the ‘Routine Enquiry’ laws mentioned earlier³²⁷. Although twenty-six U.S states have applied the ‘required request’ procedures, some states did make certain exceptions to this general duty of enquiry, especially in cases where the deceased’s wishes were already known, the medical staff were unable to locate the family in a timely manner and where such enquiry would provoke mental or emotional stress³²⁸. Eighteen states applied the routine enquiry laws, where they do not require hospitals to directly approach families but stipulate that they must establish organ and tissue donation committees to design policies which could automatically identify organ donors and make prompt referrals to the Organ Procurement Agency³²⁹. Initially, there was a positive increase in the number of organs available although, after two years, the numbers disappointingly declined³³⁰. This system was considered hard to implement and caused a lot of emotional pain as its routine policy dehumanized the relationship between the doctors and the bereaved, particularly when it initiated conversations merely based on clinical routines for the interests of others, not the

³²⁵ *Ibid*, p. 102

³²⁶ Shaun D. Pattinson, ‘*Medical Law and Ethics*’, (Sweet & Maxwell, London, 2006), p.432

³²⁷ Sheila A.M.McLean and Laura Williamson, *Xenotransplantation Law And Ethics*, (Ashgate Publishing Limited, Aldershot, 2005), p.35

³²⁸ New,B, Solomon,M, Dingwall, R, and McHale, J, ‘A Question of Give and Take: Improving the Supply of Donor Organs For Transplantation’, London: King’s Fund Institute, 1994

³²⁹ *Ibid*

³³⁰ Laura A. Siminoff, Robert M.Arnold, Arthur L Caplan, Beth A. Virnig and Debora L. Seltzer, ‘Public Policy Governing Organ and Tissue Procurement in the United States’, (1995) *Annals of Internal Medicine*, Vol. 123, No.1, July 1, 10-17

deceased's family³³¹. It was also unpopular among the doctors because it was time-consuming and emotionally demanding³³².

2.6 THE MANDATED CHOICE SYSTEM

Another system proposed to reduce the severity of organ shortage is Mandated Choice, also known as "required response"³³³. Mandated Choice requires all competent adults to freely decide whether or not they wish to become organ donors posthumously³³⁴. It is mandatory for them to make this decision³³⁵ before any eventuality renders them incapacitated³³⁶. In Virginia and Texas, licensed drivers are required to register their donation decision upon registration as a driver³³⁷. Mandated choice artificially forces persons to choose what they would want done at some point in the future rather than allowing them to delegate the decision to a surrogate they trust³³⁸. In other words, people are obliged to opt in or opt out of organ donation at some point in their lives, with their expressed views on donation taking precedence over the wishes of relatives in the event of their death³³⁹. The state would then require legally competent adults to routinely document one of the following two responses, namely:

a) Yes, I would bequeath organs for medical use;

b) No, I will not bequeath organs for medical use.

³³¹ Sheila A.M. McLean and Laura Williamson, *Xenotransplantation Law And Ethics*, (Ashgate Publishing Limited, Aldershot, 2005), p.35

³³² New, B, Solomon, M, Dingwall, R, and McHale, J, 'A Question of Give and Take: Improving the Supply of Donor Organs For Transplantation', London: King's Fund Institute, 1994

³³³ Amitai Etzioni, 'Organ Donation : A Communitarian Approach', (2003) *Kennedy Institute of Ethics Journal*, Vol.13, No.1, 1-18, p.3

³³⁴ Aaron Spital, MD, 'In The Balance Mandated Choice for Organ Donation : Time To Give It A Try' *Annals Of Internal Medicine*, (1 July 1996) Volume 125 Issue 1, 66-69, p.67

³³⁵ Chouhan, P & Draper, H, 'Modified Mandated Choice for Organ Procurement', (2003) 29 *Journal Medical Ethics*, 157-162.

³³⁶ Thomas D. Harter, 'Overcoming The Organ Shortage : Failing Means and Radical Reform', (2008) *HEC Forum* 20 (2), 155-182, p.155

³³⁷ Ann C. Klassen and David K. Klassen, 'Who are the Donors in Organ Donation? The Family's Perspective in Mandated Choice', (1996), *Annals*, Vol.125, issue 1, pp.70-73

³³⁸ Laura A. Siminoff, Robert M. Arnold, Arthur L. Caplan, Beth A. Virnig and Debora L. Seltzer, 'Public Policy Governing Organ and Tissue Procurement in the United States', (1995) *Annals of Internal Medicine*, Vol. 123, No.1, July 1, 10-17

³³⁹ The Potential Impact of An Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, Article 6.5, p.13

However, there is also a suggestion that a third option be introduced that would provide the individual with the opportunity to direct others to decide on their behalf³⁴⁰. This means that those who are undecided would be permitted to allow family members to decide for them and to have the final say, provided that this right is clearly granted to their families. However, this could also indirectly be seen as the individual informing their family members that they are not opposed to organ donation but would like to give their family the privilege of deciding what they think is best for the deceased after death occurs³⁴¹. Whatever the decision might be, these wishes must then be expressed in writing³⁴², recorded, collected and later retrieved in the event of death with donation potential³⁴³. The mandate to express choice would be easily satisfied by individuals filing signed statements with a central repository of such information, for example the Registry of Motor Vehicles³⁴⁴, part of the tax return, vehicle driver's license application forms, state benefit claims and others³⁴⁵. The objectives of this system are to ensure that peoples' wishes regarding the management of their own organs after they die are clearly known and requests to families avoided. A person's decision would be binding and could not be overridden by the family unless that person had made a provision granting his or her family the power of veto to decide on his behalf³⁴⁶. No person would be authorised to execute a written expression of choice on behalf of another adult, whether the would-be donor or non-donor is characterised as competent, once competent, or never competent at all³⁴⁷.

³⁴⁰ Susan, E. Herz, 'Two Steps To Three Choices : A New Approach To Mandated Choice', *Cambridge Quarterly of Healthcare Ethics* (1999, USA), 8,340-347, p.342

³⁴¹ *Ibid*, p.341

³⁴² *Ibid*.

³⁴³ Ann C. Klassen & David K. Klassen, 'Who Are the Donors in Organ Donation? The Family's Perspective in Mandated Choice' *Annals of Internal Medicine*, (1 July 1996), Volume 125, Issue 1, 70-73. p.70.

³⁴⁴ Susan, E. Herz, 'Two Steps To Three Choices : A New Approach To Mandated Choice', *Cambridge Quarterly of Healthcare Ethics* (1999, USA), 8,340-347, p.341

³⁴⁵ Chouhan, P & Draper, H, 'Modified Mandated Choice for Organ Procurement', (2003) 29 *Journal Medical Ethics*, 157-162.

³⁴⁶ Aaron Spital, MD, 'In The Balance Mandated Choice for Organ Donation : Time To Give It A Try' *Annals Of Internal Medicine, In The Balance*, (1 July 1996) Volume 125 Issue 1, 66-69, p.67; Chouhan, P & Draper, H, 'Modified Mandated Choice for Organ Procurement', (2003) 29 *Journal Medical Ethics* 157-162.

³⁴⁷ Susan, E. Herz, 'Two Steps To Three Choices : A New Approach To Mandated Choice', *Cambridge Quarterly of Healthcare Ethics* (1999, USA), 8,340-347, p.341

Ethically, whether the view of the family should be respected in organ requests, especially when the patient's wishes are already clearly known, remains disputable. Some predicted that ignoring and overriding family wishes would subsequently lower the rates of donation³⁴⁸. However, advocates of the proposed system countered by claiming that too much respect for and consideration of family wishes are actually the main obstacles to obtaining organs since, although there is crystal clear evidence that the deceased wished to become an organ donor, his/her wishes would only be carried out if they were accompanied by the consent of his/her family. So, mandated choice is believed to offer an alternative to obtaining consent from the family by returning control to the individual, and ensuring respect for one's right of autonomy while promoting altruism and voluntarism at the same time³⁴⁹.

Another benefit of this system is that it provides ample time for a person to consider the matter before deciding what they think is best for them. This gives them the opportunity to consider the matter clearly, in a relaxed setting, without elements of stress and pressure affecting their decisions. Once their decision has been made and recorded, they can rest assured that their wishes will be honoured and if, by any chance, they wish to alter their wishes, they are free to do so with unlimited frequency³⁵⁰. Any such alteration can be made at any time before their death and the most recent statement would prevail³⁵¹. Another advantage is that, because the system requires all adults to consider the issue of organ donation *per se*, indirectly this might also turn out to be one way to effectively increase public awareness of the value of organ donation; in the long run the aim is to eliminate occasional delays caused, in particular, by the need to obtain family consent, which can jeopardise the quality of organs harvested³⁵². This system is also capable of

³⁴⁸ Ann C. Klassen & David K. Klassen, 'Who are the Donors In Organ Donation? The Family's Perspective in Mandated Choice' *Annals of Internal Medicine*, (1 July 1996) Volume 125 Issue 1, 70-73. p70.

³⁴⁹ Aaron Spital, MD, 'In The Balance Mandated Choice for Organ Donation : Time To Give It A Try' *Annals Of Internal Medicine*, (1 July 1996) Volume 125 Issue 1, 66-69, p.67

³⁵⁰ Susan, E. Herz, 'Two Steps To Three Choices : A New Approach To Mandated Choice', *Cambridge Quarterly of Healthcare Ethics* (1999, USA), 8,340-347, p.341

³⁵¹ *Ibid.*

³⁵² Aaron Spital, MD, 'In The Balance Mandated Choice for Organ Donation : Time To Give It A Try' *Annals Of Internal Medicine*, (1 July 1996) Volume 125 Issue 1, 66-69, p.67

removing doubts about people's wishes and can help undecided people to 'come off the fence'³⁵³ by making a decision once and for all.

However, negatively, this system was said to promote coercion, particularly when people in a libertarian society are forced to decide and make choices on organ donation matters, clearly undermining their autonomy³⁵⁴. This could cause resentment and have a negative impact on organ donation issues³⁵⁵. However, according to Katz, since it is in the public interest and for the public's benefit, a negligible intrusion on an individual's privacy should be legitimately tolerated³⁵⁶. Moreover, it is not coercive with regard to the choices a person makes but in contrast beneficially ensures that those choices will be honoured³⁵⁷ without interference from others. Dworkin then pointed out that being able to choose freely is already a valuable element of life and that the possibility of choices indirectly increases the probability of satisfying our wants and provides us with greater control over life³⁵⁸. Another negative argument states that mandated choice is insensitive to the grieving family's emotions³⁵⁹ especially when relatives who oppose organ donation have to live with the knowledge that the organs of their beloved deceased were taken against their wishes³⁶⁰. In response, this situation might not be the case simply because the system actually lifts the family's burden of confronting and deciding on organ donation for the deceased while simultaneously having to cope with the unexpected loss and sadness caused by the death. By virtue of this system, they would no longer need to worry about making inaccurate guesses as to the wishes of their loved ones, which would

³⁵³ The Potential Impact of An Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, Article 6.9, p.13.

³⁵⁴ Chouhan, P & Draper, H, 'Modified Mandated Choice for Organ Procurement', (2003) 29 *Journal Medical Ethics*, 157-162.

³⁵⁵ The Potential Impact of An Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, article 6.8, p.13.

³⁵⁶ Katz, BJ, 'Increasing the Supply of Human Organs For Transplantation: A Proposal For A System Of Mandated Choice', (1984) 18 *Beverly Hills Bar Journal*. Summer, 152-167

³⁵⁷ Aaron Spital, MD, 'In *The Balance* Mandated Choice for Organ Donation : Time To Give It A Try' *Annals Of Internal Medicine*, (1 July 1996) Volume 125 Issue 1, 66-69, p.68

³⁵⁸ Dworkin .G, '*The Theory and Practice of Autonomy*'. (Cambridge: Cambridge University Press, 1998) p.8

³⁵⁹ Aaron Spital, MD, 'In *The Balance* Mandated Choice for Organ Donation : Time To Give It A Try' *Annals Of Internal Medicine*, (1 July 1996) Volume 125 Issue 1, 66-69, p.69

³⁶⁰ Chouhan, P & Draper, H, 'Modified Mandated Choice for Organ Procurement', (2003) 29 *Journal Medical Ethics*, 157-162.

at least provide some peace of mind, both for them and the organ recipients³⁶¹. Furthermore, this practice does not imply that family relations are less important or totally excluded, since they are still approached and kept well-informed on any decision and information retrieved. However, no matter how convincing the system appears to be, there is still room for doubt as there is no guarantee that it would not cause additional conflict within a family already emotionally stressed by the trauma of death, brain-death acceptance and, later, organ donation and allocation issues³⁶². It is true that, at the end of the day, it will still be the family that has to face the reality of cadaveric organ donation, not the deceased patient. So, the issue to ponder is this: can the transplantation committee afford to go against the wishes of a family for its own apparent gain, even if it is legally allowed to do so?

Mandated Choice also has logistical problems as it involves cost and it is quite a complex matter to maintain a national database of donors and the enforcement of registration.³⁶³ For countries which do not have a uniformly successful system of centralised registration of persons, the costs and complexity of such a system would be enormous and must be weighed against the potential social benefit. Success in the application of this system also depends heavily on a systematic ongoing educational campaign informing the general public about issues surrounding organ shortage³⁶⁴. Practically, this mandated choice system has not been widely practised, although it has been widely debated in the USA. Apparently, only the state of Texas had opted to implement it in 1991; unfortunately, it removed it six years later³⁶⁵. When this system was applied, it only required people to make a 'yes' or 'no' choice when renewing their driver's license. Unfortunately, partly

³⁶¹ Susan, E. Herz, 'Two Steps To Three Choices : A New Approach To Mandated Choice', *Cambridge Quarterly of Healthcare Ethics* (1999, USA), 8,340-347, p.341

³⁶² Ann C. Klassen & David K. Klassen, 'Who are the Donors In Organ Donation? The Family's Perspective in Mandated Choice' *Annals of Internal Medicine*, (1 July 1996) Volume 125 Issue 1, 70-73. p.72.

³⁶³ *Ibid*

³⁶⁴ Susan, E. Herz, 'Two Steps To Three Choices : A New Approach To Mandated Choice', *Cambridge Quarterly of Healthcare Ethics* (1999, USA), 8,340-347, p.340

³⁶⁵ *Ibid*, p.341

due to the lack of public education campaigns and weaknesses in the application system itself, the program was then officially withdrawn³⁶⁶.

CONCLUSION

Various legislative systems have been introduced and applied in different parts of the world to ensure that sufficient human organs are available to meet the high demand for them. Though these legislative systems operate differently, their main objective is still to obtain a sufficient organ supply, to help those patients in need of them. Nevertheless, their application and mode of operation differs as each system must be acceptable and suit the different types of people and society that it addresses. Indeed, factors such as custom and religion must be considered, as support from the public is crucial to ensure the success of each system applied. Due to these differences, there is no definite system available that remains free of any ethical concerns and criticisms.

It is also essential to note that there is not always a direct correlation between legal regimes and donation rates. It seems that organ donation rates are a product of different factors, not merely consent regimes. For example, countries such as Spain and the USA have high rates of organ donation, though they each apply different organ donation systems. This success is not achieved by changing one single aspect of their organ donation system, but rather by addressing each piece in the complex jigsaw of interdependent elements that make up a successful donation programme³⁶⁷. A wide range of factors, for example mortality rates from road traffic accidents, overall health expenditure, religion, education and transplant infrastructure can also influence organ donation rates within different countries³⁶⁸. And even though the high rate of organ donation in Spain (34.4 per million population in 2007) is often presented as a consequence of its presumed consent system, the President of the Spanish National Transplant Organization, Dr Rafael Matesanz, pointed out that it was not because of that factor alone, as Spain had already passed presumed consent legislation in 1979, and

³⁶⁶ *Ibid*, p.342

³⁶⁷ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, Art. 2.3, p.6

³⁶⁸ *Ibid*, Art.11.2, p. 22

donor rates only started to rise dramatically after the national transplant organization was founded and new infrastructures put in place³⁶⁹. Similarly, in Austria and Singapore many other changes were introduced simultaneously at the time of legislation, including providing better infrastructure, increasing funding for transplant programmes and also increasing awareness regarding the need for organ donation, which makes it hard to assess the exact contribution of presumed consent legislation alone³⁷⁰.

Nonetheless, whatever organ donation system is adopted, each and every system introduced must be appreciated, as each has its own strengths and weaknesses. Without prejudice, these systems are all introduced to procure as many organ donations as possible to meet the high demand for these much-needed human organs. Hopefully, with continuous reviews, research and effort, one day a perfect solution will be discovered exclusively for Malaysia too.

³⁶⁹ *Ibid*, Art.11.3-11.3, p.22

³⁷⁰ *Ibid*, Art. 11.1, p.22.

CHAPTER 3

ORGAN DONATION IN MALAYSIA

INTRODUCTION

This chapter will focus on the practice of organ donation in Malaysia and the current scenario in which organ donation is not popular and has led to severe organ shortage problems. It will look into organs harvested from both living and cadaver donors, including an elaboration of the different legal procedures applicable in organ donation involving both living and cadaver donors. An analysis of the Human Tissues Act 1974, which is the main current legislation applicable in regulating this procedure, is included in order to identify any existing weaknesses and to suggest any necessary improvements. An analysis of the National Organ, Tissue and Cell Transplantation Policy, released by the Ministry of Health in June 2007, is also included. Lastly, local problems and challenges faced in promoting organ donation are also highlighted; these evolve from the social, legal and religious restrictions faced.

3.1 AN ANALYSIS OF THE MALAYSIAN HUMAN TISSUES ACT 1974

The sole legislation available in Malaysia to regulate organ transplantation is the Human Tissues Act 1974. This Act was first published in the Gazette on 14th March 1974 and became effective from 1st January 1975. Although this Act has now been in operation for three decades, it is still applicable in its original state; to this day, no additional amendments have been made. This five-sectioned Act starts with a section that clearly introduces itself as the Human Tissues Act 1974 and sets down its jurisdiction which makes it applicable throughout Malaysia. This Act focuses mainly on cadaver donors and requires any person willing to become an organ donor to specifically make known his/her wishes either in writing or, if the request is made orally, in the presence of two or more witnesses present during his/her final illness³⁷¹. The donor must expressly request that

³⁷¹ Section 2 (1) Human Tissues Act 1974

his/her body or any specified part of the body is to be used after his death and must decide whether it should be used for therapeutic purposes, medical education or research³⁷². The Act further states that the person lawfully in possession of the body may, after death, authorise removal of the specified body parts according to the request made, after ensuring that the deceased had not expressed any retractions soon after the request. The person lawfully in possession of the deceased body, after making reasonable and practicable enquiry, may also permit donation where, after making reasonable and practicable enquiry, he/she believes:

- a) that the deceased had not expressed an objection to his/her body being dealt with after his/her death³⁷³ or
- b) that the surviving spouse or any surviving next of kin of the deceased has not objected to the body being used for the above-mentioned purposes³⁷⁴.

However, it must be noted that the ‘person lawfully in possession of the body’ is not bound to carry out the deceased’s wishes. He/she is empowered but not obliged to act. So, he/she can withhold permission, whether rationally or not, if he/she has any reason to do so³⁷⁵. Though this ‘person’ seems to have strong discretionary powers to decide, there is unfortunately no specific interpretation provided which clarifies who this ‘person in lawful possession’ should refer to. Previously, under the Anatomy Act 1832 in the UK, authority goes to the next of kin or the executors of the deceased to claim the body; if

“If any person, either in writing at any time or orally in the presence of two or more witnesses during his last illness, has expressed a request that his body or any specified part of his body be used after his death for therapeutic purposes, or for purposes of medical education or research, the person lawfully in possession of his body after his death may, unless he has reason to believe that the request was subsequently withdrawn, authorise the removal from the body of any part or, as the case may be, the specified part, for use in accordance with the request”.

³⁷² *Ibid*

³⁷³ Section 2(2)(a) Human Tissues Act 1974

“(2) Without prejudice to the foregoing subsection, the person lawfully in possession of the body of a deceased person may authorize the removal of any part from the said body for use for the purposes aforesaid if, having made such reasonable enquiry as may be practicable, he has no reason to believe-(a) that the deceased had expressed an objection to his body being so dealt with after his death; or”

³⁷⁴ Section 2(2)(b) Human Tissues Act 1974

(b) “that the surviving spouse or any surviving next-of-kin of the deceased objects to the body being so dealt with.”

³⁷⁵ Dworkin,G, ‘The Law Relating to Organ Transplantation in England’, (1970) 33, *The Modern Law Review*, No.4, 353

there is none, the hospital authority would be lawfully in possession of it³⁷⁶. Departments of Health have advised that, in the case of deaths in hospitals, until relatives claim the body, the person in possession of the body is the hospital management committee or board of governors or anyone designated so to act on their behalf³⁷⁷. However, as the term was not fixed and sometimes referred to executors and sometimes to the hospital administration officers, this resulted in a lot of confusion³⁷⁸. Therefore, an exact and clear definition is essential to clarify the identity of the eligible persons having authority to possess the deceased's body and act accordingly with it. Otherwise, the present wording will continuously lead to confusion. Nevertheless the Human Tissues Act 1974 does state that no authorisation to remove any body parts of the deceased shall be given by a person entrusted with the body for the purpose of its interment or cremation³⁷⁹. With reference to the above, only removals and use of any body parts that are conducted in accordance with the above requirements are treated as valid and lawful³⁸⁰.

Section 3(2) further requires that every removal must be done only by a medical practitioner who is fully registered under the Medical Act 1971, soon after a thorough personal examination of the body has been conducted, together with at least one other fully registered medical practitioner. Both must be satisfied that life has definitely left the deceased³⁸¹. As for unclaimed bodies of deceased persons left in hospitals, by virtue of section 4 these bodies are to be directly under the authorisation and management of the

³⁷⁶ Section 7, Anatomy Act 1832

³⁷⁷ Circular H.M (61) 98 in Dworkin, G, 'The Law Relating to Organ Transplantation in England', (1970) 33, *The Modern Law Review*, No.4, 353

³⁷⁸ Mason, JK, Laurie, GT and Aziz, M *Mason & Mc Call Smiths's Law and Medical Ethics*, 7th. Edition, (United States, Oxford University Press, 2006), p.492.

³⁷⁹ Section 2(3) Human Tissues Act 1974

(3) "No authorisation shall be given under this section in respect of any body by a person entrusted with the body for the purpose only of its interment or cremation."

³⁸⁰ Section 3(1) Human Tissues Act 1974

(1) Subject to subsections (2) and (3), the removal and use of any part of a body in accordance with an authorisation given in pursuance of section 2 shall be lawful."

³⁸¹ Section 3(2) Human Tissues Act 1974

(2) "No such removal shall be effected except by a medical practitioner fully registered under section 14 of the Medical Act 1971 [Act 50], and who together with at least one other fully registered medical practitioner have satisfied themselves by personal examination of the body that life is extinct."

hospital or any other person authorised as the person deemed to have lawful possession of the dead body³⁸².

Comparing the Malaysia Human Tissues Act 1974 with the United Kingdom Human Tissue Act 2004, it is clear that, although the names are quite similar, the contents are totally different. Scrutinising the Malaysia Human Tissues Act 1974, even though the phrase “human tissues” is used as the name of the Act, the five sections contained within it prefer to use the phrase “body or any specified part of the body”, which is assumed to refer to organs and tissues. There is, however, no exact interpretation found for the phrase used, which makes it rather imprecise and unclear as to what it actually means and refers to. Therefore, it remains vague whether there are any limitations for those organs and tissues eligible for donation and transplantation purposes.

Similarly, although the UK Human Tissue Act 2004 does not define the word “organs” either, at least section 53 of the Act states that the phrase “relevant material” includes tissue, cells and human organs excluding gametes, embryos outside the body, and hair and nails from a living person. In addition, section 54(7) of the same Act also excludes cell lines within the definition. However, despite the above indirect definition, there is still a view that the definition provided is too broad, as it does not draw a distinction between using samples of organs and taking the organ as a whole³⁸³.

The Human Organ Transplants Act 1989, in section 7(2) previously applicable in the UK, did define organs as “any part of a human body consisting of a structured arrangement of tissues, which if wholly removed, cannot be replicated by the body”; however, this definition was not incorporated within the latest (2004) Act. Nevertheless, if the Malaysia Human Tissues Act 1974 is to be amended in the future, a precise definition of the phrase

³⁸² Section 4 Human Tissues Act 1974

“In the case of a body of a deceased person lying in a hospital and unclaimed the person having the control and management of the hospital or any other person authorized by him shall be deemed for the purpose of this Act to be a person in lawful possession of the body.”

³⁸³ See discussion by Jonathan Herring, *Medical Law and Ethics* (United States, Oxford University Press, 2006) p. 360

“body or any specified part of the body” should be included as it is absolutely essential to be clear and precise, particularly when it involves law and its application to the public.

It is also advised that a specific definition of the phrase “next of kin” as found in the wording of section 2(2)(b) be incorporated by including a specific list of relatives deemed to be on the list of next of kin. Considering the cultural factors whereby Malaysians are very much influenced by and close to their families, including extended families, there is indeed a need to specify the limit. From a practical point of view, the Malaysian Medical Association suggests that the phrase be confined to the surviving spouse and children. However, in cases where there is no spouse, or for those who are unmarried, it should be the parents, and in cases involving children it should be limited to their parents or legal guardian³⁸⁴.

Malaysian laws on organ procurement and transplantation are very much consent-based. It is a requirement that any tissue or organ removal must be supported by express consent of the donor him/herself, which is made either in written form or, if orally, in the presence of at least two witnesses before his/her death. Although consent is required, the actual concept of consent as required by the Act still seems unclear. There is no certain parameter available as to how much information must be obtained in order to classify the consent given as effective. This point is even more crucial in situations where “the person having possession of the deceased body” is allowed to authorise the removal of any part of the deceased’s body once he/she believes that the deceased had not expressed any objections to his/her body or body parts being dealt with after his/her death. Thus, it is recommended that there be some guidance available on the level of information needed to ensure effectiveness of the consent obtained. For instance, if the deceased had left no directions and had not been known to have previously consented to any organ removal, or there is an objection by close relatives, then the body should be prepared for burial or

³⁸⁴ Malaysian Medical Association. Donor Organ Transplant, 1 March 2003, http://www.mma.org.my/current_topic/organ.htm.p.1. viewed on 1 September 2007.

disposal accordingly. Therefore, in all these cases, the deceased's organs must be left untouched and originally intact inside the body.

Additionally, section 2(2) (b) of the 1974 Act clearly provides optional power to the surviving spouse or next of kin to authorize removal of any part of the deceased body, though it is still subject to any express objections by the deceased him/herself during his/her lifetime or any family objections brought forward. While this step is beneficial in saving potential organs from being wasted, in the author's opinion the deceased party seems to have been left with little authority over his/her own body. What if the deceased had never expressed his/her view about organ donation with anybody, and was actually against it? This provision also shows how respect and consideration are accorded to the deceased's family in making such a big decision on behalf of the deceased party. Nevertheless, one can still argue that, if the wishes of the relatives are respected, this indirectly reflects the deceased's own wishes, as presumably the deceased would not want any further distress caused to his/her relatives after his/her death³⁸⁵.

Another weakness of the Human Tissues Act 1974 is that it does not provide for any civil or criminal sanctions and definite punishments if any organ procurement procedure has been disregarded or infringed. This lacuna makes it almost impossible to take action against any person who commits this offence. Comparatively, the Human Tissue Act 2004 in the UK addresses such non-observance from a criminal perspective. For example, falsely representing that there is "appropriate consent" and retaining organs without consent is considered a criminal offence which carries a maximum sentence of three years³⁸⁶. Malaysia must also have penalties for activities like taking, retaining, or using human organs and tissues without consent, including trafficking in human body parts³⁸⁷.

The Human Tissue Act 1974 mainly focuses on therapeutic parts obtained from cadaver donors, but it is totally silent on requirements needed to govern and regulate cases

³⁸⁵ Jonathan Herring, *Medical Law and Ethics* (United States, Oxford University Press, 2006) p. 383.

³⁸⁶ Section 5(2) Human Tissue Act 2004.

³⁸⁷ George Galea and D Pegg, 'The Ethics of Donation : Changes are Necessary and Soon', (2003) *The Lancet*, Vol.362, 20 September

involving living donors. Consequently, living donation procedures remain vague and uncertain, causing misunderstandings and confusion within society. Only after the introduction of the National Organ, Tissue and Cell Transplantation Policy by the Ministry of Health, Malaysia in June 2007 has it become clear that organ and tissue procurement from living donors are allowed in Malaysia, particularly from those are blood relatives of the recipient him/herself³⁸⁸. Nevertheless, the element of consent by the donor is essential, as it must be given freely, without coercion or any such commercial incentive being involved³⁸⁹. The Act is also silent on issues regarding the age limit for donation, concealment of donor's identity from the donee and public, and the prohibition of organ-purchasing. A clear definition of brain death is also required as most doctors in Malaysia accept and practise the concept of brain death³⁹⁰.

Interestingly, in general the Human Tissues Act 1974, Malaysia, is found to be quite similar in content to the Human Tissue Act of 1961. For instance, the wordings of section 2 (1) of the Human Tissues Act 1974, Malaysia, is exactly the same as section 1(1) of the Human Tissue Act 1961, and Section 2(2) (a) and (b) of the 1974 Act is a repetition of section 1(2) (a) and (b) of the old 1961 Act in the UK. As for sections 3, 4 and 5 of the 1974 Act, although they carry the same content as sections 1(3), (4), (5) and (7) of the 1961 Act, the wordings differ slightly, so as to suit the situation applicable in Malaysia. For instance, section 4 of the 1974 Act in Malaysia only mentions bodies of deceased persons lying in a hospital, but the actual 1961 Act had also mentioned nursing homes or other institutions, besides the hospital. This is because, in Malaysia, nursing homes are not common, as the elderly are normally looked after by their children until they die. This similarity could be due to the fact that Malaysia follows English Common Law in a lot of matters. However, the current UK Human Tissue Act 2004 has answered most of

³⁸⁸ Basri Ibrahim al-Hassani al-Azhari, The Current Practice of Organ Transplantation in Malaysia, *Journal of Human Sciences*, Issue 45, yr7, January 2010, [www.ulum.nl/THE CURRENT PRACTICE OF ORGAN TRANSPLANTATION IN MALAYSIA.pdf](http://www.ulum.nl/THE_CURRENT_PRACTICE_OF_ORGAN_TRANSPLANTATION_IN_MALAYSIA.pdf), viewed on 1 June 2011

³⁸⁹ Article 6.2.1 National Organ, Tissue and Cell Transplantation Policy, Ministry of Health Malaysia, June 2007

³⁹⁰ Guideline of The Medical Council, Organ Transplantation, MMC Guideline 006/2006, [http://www.agiftolife.gov.my/pdf/Organ transplantation Malaysian Medical Council.pdf](http://www.agiftolife.gov.my/pdf/Organ_transplantation_Malaysian_Medical_Council.pdf), p.13, viewed on 1 October 2010

the prevailing ambiguities found in the 1961 Act and has repealed all other earlier legislation including the Human Tissue Act 1961, the Anatomy Act 1984, the Corneal Tissue Act 1987 and the Human Organ Transplants Act 1989³⁹¹. The Act also authorises certain consensual activities relating to human bodies and body parts and imposes licensing requirements for certain activities. Provisions for de-accession of human remains and various offences are also incorporated within it³⁹², while it retains an emphasis on the requirement of consent upon both living and cadaver donors, involving bodies or material from both adults and minors. Even a hierarchy of those having authority over the deceased has been ranked specifically in order to clarify any ambiguity and avoid difficulties in managing these human tissues. As the laws in the UK on human tissues and organs continue to grow and develop to address any contemporary issue, it is suggested that Malaysia, too, should take a step forward and update its Human Tissues Act 1974, at least to provide for better coverage of all issues related to organ donation and transplantation taking place locally.

However, with the publication of the National Organ, Tissue and Cell transplantation Policy in June 2007, the position became clearer. Besides promoting organ donation³⁹³, the policy aims to provide transparent and equitable access to transplant procedures³⁹⁴ which are to be carried out with the highest ethical and professional standards³⁹⁵. Additionally, it also aims to provide the highest quality of care including proper documentation and maintenance of registries³⁹⁶. Interestingly, while the policy exclusively mentions its aims to promote cadaveric organ donation, it simultaneously pledges to give full commitment to protecting the rights and welfare of living donors as well. As a whole, the introduction of this new policy clearly shows the government's support in helping to promote organ donation as a preferred treatment in end-stage organ

³⁹¹ Lord Mackay of Clashfern, (2005), 30(1) Medical Professions Halsbury's Laws of England, 4th.edition Reissue. Lexis Nexis Butterworth. 1987-97, p.251.

³⁹² *Ibid*

³⁹³ Article 2.1, National Organ, Tissue and Cell Transplantation Policy, Ministry of Health, Malaysia, June 2007

³⁹⁴ Article 2.3, National Organ, Tissue and Cell Transplantation Policy Ministry of Health, Malaysia, June 2007.

³⁹⁵ Article 2.4, National Organ, Tissue and Cell Transplantation Policy Ministry of Health, Malaysia, June 2007

³⁹⁶ Article 2.6, National Organ, Tissue and Cell Transplantation Policy Ministry of Health, Malaysia, June 2007

failure. Moreover, as this policy is supplementary to the existing 1974 Act, it is flexible and allows reviews to take place every three years or as the necessity arises³⁹⁷. However, one clarification that it fails to include is the extent to which it is applicable besides the Human Tissues Act 1974. The policy also fails to mention, in its preamble, those who are subject to it and whether any consequences will follow from any non-compliance with it.

3.2 SOURCES OF ORGANS IN MALAYSIA

Malaysia practises organ donations from living and cadaveric donors, with different procurement procedures available for each type respectively. Guidelines for any cadaveric transplantation are laid down in the Human Tissues Act 1974. Unfortunately, the same Act is totally silent on transplantation involving living donors. So, a new policy was introduced by the Ministry of Health in June 2007 to address other issues related to organ, tissues and cell transplantation in Malaysia, particularly those not covered by the Act.

3.2.1 CADAVERIC DONORS

Cadaveric organ and tissue donations are considered preferable in Malaysia³⁹⁸ as they provide the largest supply of organs with the least risk to the donor. This group of non-living donors are normally those who have died due to brain death and had bequeathed their organs or tissues when they were still alive (a pre-arranged donation). This normally takes place when they die in intensive care and artificial breathing and heartbeat are kept going until the donated organs have been retrieved. Despite promotions and campaigns to boost cadaveric donations, each year Malaysia faces the problem of a decline in the number of cadaveric donors. For instance, in 2002 there were 30 cadaver donors but this

³⁹⁷ Article 1.10, National Organ, Tissue and Cell Transplantation Policy Ministry of Health, Malaysia, June 2007

³⁹⁸ Article 2.2 and Article 6.1. National Organ, Tissue and Cell Transplantation Policy, Ministry of Health Malaysia, June 2007.

dropped to 25 in 2003 and only 16 in 2004³⁹⁹. 2005 recorded another obvious drop as only 13 from a total of 62 expected donors proceeded with their donations⁴⁰⁰. The Fourth Report of the National Transplant Registry still reported a decline in the number of potential donor referrals made in 2007. Here, from a total of 73 potential donor referrals made, only 25 actual donations materialised, of which 15 were brain-dead donors who donated organs and tissues which were procured in the operating theatre, while another 10 were tissue donations after cardiac death⁴⁰¹.

The Human Tissues Act 1974 of Malaysia generally mentions basic procedures for cadaver conscription; however, a more detailed structure is now available in the National Organ, Tissue and Cell Transplantation Policy. Now, with the existence of a Transplantation Procurement Management Unit (TPMU) at a national level, all aspects of organ and tissue procurement from cadaveric donors are specifically managed and coordinated by this unit⁴⁰². Among other things, the unit will liaise with the transplant team to ensure a safe and efficient transport from donor hospital to recipient hospital, provide guidelines and standard procedures, conduct public education and maintain regular data on all activities related to organ and tissue transplants. As for hospitals acknowledged as having the ability to proceed with transplants, each will now have their own Tissues Organ Procurement Team (TOP) which consists of trained personnel responsible for identifying potential donors, including obtaining consent from next of kin, making evaluations regarding donation, organising the procurement procedure, and organising storage and transportation of the organs and tissues including ensuring that the donors' remains are returned to their next of kin as soon as possible⁴⁰³. According to the policy, all potential cadaveric donations shall be made known to the local Tissue Organ Procurement Team⁴⁰⁴ and all deaths shall be considered as possible circumstances for

³⁹⁹ LelaYasmin Mansor, 'Cadaveric Organ and Tissue Donation', Second Report of the National Transplant Registry 2005, (Kuala Lumpur, National Transplant Registry, 2006), p.151

⁴⁰⁰ *Ibid*

⁴⁰¹ LelaYasmin Mansor, 'Cadaveric Organ and Tissue Donation', Fourth Report of the National Transplant Registry 2007, (Kuala Lumpur, National Transplant Registry, 2007), p.170

⁴⁰² Article 6.3 National Organ, Tissue and Cell Transplantation Policy, Ministry of Health Malaysia, June 2007

⁴⁰³ *Ibid*, Article 6.3.1.2

⁴⁰⁴ *Ibid*, Article 6.3.2

donations⁴⁰⁵. The TOP team will also provide support and follow-up care to the donor's family for an appropriate duration⁴⁰⁶. In determining and certifying the deaths of these potential cadaveric donors, such verification must be carried out by registered medical practitioners who are independent of the organ transplantation team⁴⁰⁷. And, in cases where the potential cadaveric donors' remains are being held under the Criminal Procedure Code for post-mortem or coronal inquest, prior written consent must be obtained from the magistrate before any organ procurement procedures can take place⁴⁰⁸. However, the policy regarding consent to donate organs is definitely in line with the existing Human Tissues Act, 1974, as it requires express consent from the deceased, made through the donor pledge or from the next of kin⁴⁰⁹. Unfortunately, again, the phrase 'next of kin' is still left vague and undefined.

3.2.2 LIVING DONORS

The autonomy principle allows us to dispose of our body and body parts non-commercially as long as it is in our best interest to do so or, at least, as long as it does not harm us⁴¹⁰. For example, when a parent donates one of his/her kidneys or part of their liver to their sick child, it creates a feeling of satisfaction in them for being able to do almost anything to help save their child's life; however, their donation must not be an act which will then cause harm or danger to their own lives. Centred on the above concept, organ donation and transplantation involving living donors is an accepted practice in Malaysia, but its application is based on certain guidelines. First, the potential living donor must be an adult legally able to give consent and completely aware of all the risks that can occur due to the decision to become a living donor. Besides being physically and mentally fit, he/she must be fully aware of the decision he/she is making, including understanding all the relevant information; he/she must also be able to evaluate his/her position and the decision he/she is making must be free from any elements of duress and

⁴⁰⁵ *Ibid*, Article 6.3.3

⁴⁰⁶ *Ibid*, Article 6.3.4

⁴⁰⁷ *Ibid*, Article 6.3.5

⁴⁰⁸ *Ibid*, Article 6.3.6

⁴⁰⁹ *Ibid*, Article 6.3.7

⁴¹⁰ Sheila Mc Lean & John Kenyon Mason, *Legal & Ethical Aspects of Healthcare* (London, Greenwich Medical Media Limited, 2003) p.179.

coercion⁴¹¹. Living donors are preferably blood relatives of the recipient but there are special cases where close non-related family donors are also willing to become donors. Fortunately, nowadays, due to advancements in technology, non-related transplant donors are becoming more feasible especially with improvements in the use of anti-rejection drugs and the cross-matching of tissues of donors and patients⁴¹².

Although the Human Tissues Act 1974 is silent on living donations, article 6.2 of the Policy provides that organ and tissue procurements from living donors are allowed, but the donors shall preferably be related to the recipients and the donor's consent must be given freely and altruistically without any coercion or commercial inducements⁴¹³. In other words, Malaysia practises a living related donor programme⁴¹⁴ which means that the donor and the recipient must be blood-related to each other. This includes relationships such as:

- i. parents or children
- ii. grandmother/grandfather
- iii. siblings of the same mother and same father
- iv. siblings with either the same mother but different father or the same father but a different mother
- v. uncle or aunt
- vi. first cousins⁴¹⁵

Emotionally related relationships are also allowed including:

- i. those with a long-standing friendship with the recipient
- ii. wife/husband of the recipient.⁴¹⁶

⁴¹¹ Article 6.1,a-f, Guideline of The Malaysian Medical Council Organ Transplantation, MMC Guideline 006/2006, [http://www.agiftoflife.gov.my/pdf/Organ Transplantation-Malaysian Medical Council.pdf](http://www.agiftoflife.gov.my/pdf/Organ%20Transplantation-Malaysian%20Medical%20Council.pdf), p.20, viewed on 1 June 2011

⁴¹² David W. Meyers. *The Human Body and the Law*, Second edition, (Edinburgh University Press, Edinburgh, 1990) p.182.

⁴¹³ Article 6.2.1 National Organ, Tissue and Cell Transplantation Policy, Ministry of Health Malaysia, June 2007

⁴¹⁴ Fabiola D'Cruz and N.Chandrasekharan. Malaysia Medical Association, Renal Disease in Malaysia: Problems and Prospects. http://www.mma.org.my/info/2_renal_90.htm_p.3, viewed on 1 September 2007.

⁴¹⁵ Article 3.1, Guideline of The Malaysian Medical Council Organ Transplantation, MMC Guideline 006/2006, [http://www.agiftoflife.gov.my/pdf/Organ Transplantation-Malaysian Medical Council.pdf](http://www.agiftoflife.gov.my/pdf/Organ%20Transplantation-Malaysian%20Medical%20Council.pdf), p.18, viewed on 1 June 2011.

However, one common problem faced is when the needed organs cannot be obtained from parents or siblings as they do not match the recipient, and close relatives are quite reluctant to donate their organs. Reluctance to donate can be due to concerns that negative effects and risks following the procedure might materialise, as living donations can cause physiological maleficence to the donor⁴¹⁷. Generally, this includes possibilities of inevitable harm such as pain and scarring to the wound site, risks of morbidity, long-term complications and risks of mortality, though the percentage for this is relatively low⁴¹⁸. However, all these factors must be considered as they can contribute in causing difficulty and failure to obtain the needed organ. That is why, in certain exceptional cases, with permission obtained from the appointed ethical committee, there are only selective occasions where non-related living donors are allowed to take part in the procedure. However, this exception is subject to strict scrutinisation by the Unrelated Transplant Committee (UTAC)⁴¹⁹ to avoid any elements of organ-trading and to ensure the level of risks involved is very low⁴²⁰. This matter is considered very seriously to avoid cases where the donor actually does not quite understand the potential risks that might consequently occur. For instance, there is the risk of death, even though it is relatively low, at about 0.3-0.5%, and most donors are unable to work normally for a certain length of time⁴²¹. According to Dr. Ghazali Ahmad, consultant and Head of the Nephrology Department, Kuala Lumpur General Hospital, strict investigation and scrutinisation is necessary before any case of unrelated donor is approved, to check on the motives for the donation, while ensuring that no financial incentives or trading

⁴¹⁶ Article 3.2, Guideline of The Malaysian Medical Council Organ Transplantation, MMC Guideline 006/2006, [http://www.agiftoflife.gov.my/pdf/Organ Transplantation-Malaysian Medical Council.pdf](http://www.agiftoflife.gov.my/pdf/Organ%20Transplantation-Malaysian%20Medical%20Council.pdf), p.18, viewed on 1 June 2011.

⁴¹⁷ Austen Garwood –Gowers, *Living Donor Organ Transplantation: Key Legal and Ethical Issues*, (Aldershot, Ashgate, 1999) , p.33

⁴¹⁸ *Ibid*, pp.41-46

⁴¹⁹ *Ibid*, Article 6.2.3 Guideline of The Malaysian Medical Council Organ Transplantation, MMC Guideline 006/2006, [http://www.agiftoflife.gov.my/pdf/Organ Transplantation-Malaysian Medical Council.pdf](http://www.agiftoflife.gov.my/pdf/Organ%20Transplantation-Malaysian%20Medical%20Council.pdf), p.18, viewed on 1 June 2011.

⁴²⁰ Rosmawati Mion. ‘Kaji Semula Derma Organ Tiada Kaitan Saudara’. *Utusan Online*. 17 August 2004 . http://www.utusan.com.my/utusan/archive.asp?y=2004&dt0817&pub=utusan_mala. Viewed on 2 April 2007.

⁴²¹ *Ibid*

elements are involved⁴²². Unfortunately, these justifications and reasons are not sufficiently highlighted to the public at large⁴²³, which can cause irresponsible allegations to be made against the government, such as being too strict or having no sympathy with such patients.

Article 6.2.1 of the National Organ, Tissue and Cell Transplantation Policy requires every act of consent to be obtained freely and altruistically, without any elements of coercion or any commercial inducement involved. Article 6.2.2 of the policy restricts minors from becoming living donors, except in cases where regenerative tissues are involved. Prior authorisation from the Unrelated Transplant Approval Committee (UTAC) must be obtained, although consideration will be given in cases where there is no cadaveric donor available⁴²⁴, no genetically- or emotionally-related family members are found to be compatible⁴²⁵ and there is no alternative treatment available⁴²⁶. Initially, all living donors shall be counselled by donor advocates⁴²⁷ regarding the risks, benefit and possible consequences, to ensure that they are well-informed and are totally aware of any consequences that might ensue as a result of their decision to become living donors⁴²⁸. All procurement and transplantation procedures must take place only at accredited centres⁴²⁹ and be carried out by credentialed personnel⁴³⁰. Unfortunately, the list of these centres and the criteria needed to qualify as credentialed personnel are not further elaborated. These accredited centres must follow and apply the written guidelines and standard operating procedures⁴³¹ including verifying a person's eligibility to become

⁴²² Interview conducted on 12 February 2008 at the Nephrology Department, Kuala Lumpur General Hospital, Malaysia.

⁴²³ *Ibid*

⁴²⁴ Article 6.2.3.1 National Organ, Tissue and Cell Transplantation Policy, Ministry of Health, Malaysia, Ministry of Health Malaysia, June 2007.

⁴²⁵ Article 6.2.3.2 National Organ, Tissue and Cell Transplantation Policy Ministry of Health, Malaysia, June 2007

⁴²⁶ Article 6.2.3.3 National Organ, Tissue and Cell Transplantation Policy Ministry of Health, Malaysia, June 2007

⁴²⁷ Donor advocates shall be those independent of the organ procurement and transplantation team to avoid bias and maintain translucent.

⁴²⁸ Article 6.2.4 National Organ, Tissue and Cell Transplantation Policy, June 2007

⁴²⁹ Article 6.2.7 National Organ, Tissue and Cell Transplantation Policy, June 2007

⁴³⁰ Article 6.2.7 National Organ, Tissue and Cell Transplantation Policy, June 2007

⁴³¹ Article 6.2.8 National Organ, Tissue and Cell Transplantation Policy, June 2007

a donor⁴³², having a detailed donor evaluation including both psychosocial and medical assessment⁴³³ and, lastly, having a plan for life-long donor follow-ups⁴³⁴ in the future.

As for the potential living donor, he/she must have access to all available information before signing the consent form⁴³⁵. The potential donor must understand the types of tests which need to be carried out, and the risks and complications of such tests, the short- and long-term risks, including the risk of death, the success rate of the transplantation in general and the success rate of the institution performing the transplantation, and the need for follow-up treatment⁴³⁶. Enough time must be given for such consent to be obtained and the doctor involved must ensure that the freedom to give consent is provided. The potential donor must also be appraised that he/she may withdraw consent at any time without giving any reason and that no action will be taken against him/her⁴³⁷.

3.3 THE ORGAN PROCUREMENT SYSTEM IN MALAYSIA

Malaysia, as a vast developing country with an estimated population of 28.31 millions in 2009⁴³⁸, is among the countries with the lowest number of donors. Practising the 'opting in' system, the registered donor will be provided with a small, green, organ donor card which specifies which organs he/she has agreed to donate. This card should be carried by the donor at all times to ensure that they can be easily identified if the situation arises. However, one disadvantage of this identification donor card is that not everybody makes a habit of carrying the card with them all the time. To make things worse, Malaysia has

⁴³² Article 6.2.8.1 National Organ, Tissue and Cell Transplantation Policy, June 2007

⁴³³ Article 6.2.8.2 National Organ, Tissue and Cell Transplantation Policy, June 2007

⁴³⁴ Article 6.2.8.3 National Organ, Tissue and Cell Transplantation Policy, June 2007

⁴³⁵ Article 6.3, Guideline of The Malaysian Medical Council Organ Transplantation, MMC Guideline 006/2006, [http://www.agiftoflife.gov.my/pdf/Organ Transplantation-Malaysian Medical Council.pdf](http://www.agiftoflife.gov.my/pdf/Organ%20Transplantation-Malaysian%20Medical%20Council.pdf), p.20, viewed on 1 June 2011

⁴³⁶ *Ibid*

⁴³⁷ Article 6.5, Guideline of The Malaysian Medical Council Organ Transplantation, MMC Guideline 006/2006, [http://www.agiftoflife.gov.my/pdf/Organ Transplantation-Malaysian Medical Council.pdf](http://www.agiftoflife.gov.my/pdf/Organ%20Transplantation-Malaysian%20Medical%20Council.pdf), p.21, viewed on 1 June 2011

⁴³⁸ Department of Statistics Malaysia Official Website, <http://www.statistics.gov.my/eng/index.php?option=com>, updated on 31 July 2009, Viewed on 7 October 2009.

unfortunately still not fully developed its organ donor database which would be able to retrieve the list of its registered organ donors automatically⁴³⁹.

Generally, all matters relating to organ donation and transplantation are under the control of the Ministry of Health of Malaysia. Initially, in 1999, Tissue Organ Procurement (TOP) teams were established in sixteen Ministry of Health hospitals to facilitate the management of cadaveric organ and tissue donations in these hospitals. Later, as the establishment of these TOP teams managed to raise the number of annual cadaveric donations in the following years, a few other public, university and private hospitals followed in their footsteps and set up their own TOP teams as well⁴⁴⁰. Then, in 2001, the National Transplant Procurement Management Unit was established to centralise coordination of the management of cadaveric donors and procurement of organs and tissues at the national level⁴⁴¹. This Unit cooperates with the local TOP teams who manage donors at their hospital level, the recipient transplant teams, and the organ and tissue retrieval teams. The unit will then arrange the logistics of transporting the retrieval teams to the donor and bringing back the organs and tissues to the respective centres for transplantation. Besides that, the unit is also responsible for the promotion and central registration of donor pledges including training the hospital staff and increasing the public and hospital personnels' awareness of organ donation in general⁴⁴².

Subsequently, in November 2003, the National Transplant Registry (NTR) was set up through initiatives of the Clinical Research Centre and the Malaysian Society of Transplantation, supported by a grant from the Ministry of Health and with financial contributions from various interested parties⁴⁴³. However, after December 2005, the running of the NTR was transferred to the Malaysian Society of Transplantation but continued to be a Ministry of Health registry that collects information about organ and

⁴³⁹ Interview on 12 February 2008 with Dr. Ghazali Ahmad, consultant and Head of Nephrology Department, Kuala Lumpur General Hospital, Malaysia,

⁴⁴⁰ Hooi LS and Lela Yasmin Mansor, *1st Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005), p.128.

⁴⁴¹ *Ibid*

⁴⁴² *Ibid*

⁴⁴³ Lela Yasmin Mansor, *1st Report of the National Transplant Registry 2004*, (Kuala Lumpur, National Transplant Registry, 2005), p.3.

tissue transplantations in Malaysia⁴⁴⁴. The NTR has databases which monitor and describe all local trends in transplantation taking place while organising and ensuring that every donation is coordinated according to the legal requirements set out⁴⁴⁵. Besides evaluating transplantation services in Malaysia, NTR also aims to stimulate and facilitate research on transplantation and its management while ensuring the outcome and factors influencing transplantations⁴⁴⁶.

Currently, however, one weakness within Malaysia's organ donation system is that it lacks a procedure to identify and retrieve organs from all registered organ donors automatically and have the main local hospitals directly linked and with access to such a list⁴⁴⁷. Another limitation which restrains local organ procurement activities is that NTR is unable to make regular updates as it is not possible for them to trace the exact location of death involving their registered organ donors, except in cases where the family members of the deceased donor notify or inform NTR of the occurrence of such a death of their family member⁴⁴⁸. However, in most cases, not even the deceased's family members themselves are aware of the fact that the deceased was actually a registered organ donor as they were never informed by the deceased nor did the deceased leave any indications showing such intentions⁴⁴⁹. Besides that, Jamaliah Kario further elaborated that NTR has staff shortages and, although staff training is provided, the same issue repetitively arises as their staff are not permanent and are subject to transfers to other units and departments as well.

⁴⁴⁴ Hooi LS and Lela Yasmin Mansor, *2nd. Report of the National Transplant Registry 2005*, (Kuala Lumpur, National Transplant Registry, 2006), p.vii.

⁴⁴⁵ Tan Chwee Choon, *2nd. Report of the National Transplant Registry 2005*, (Kuala Lumpur, National Transplant Registry, 2006), pp.1-2.

⁴⁴⁶ Lela Yasmin Mansor, *2nd. Report of the National Transplant Registry 2005*, (Kuala Lumpur, National Transplant Registry, 2006), p.vii.

⁴⁴⁷ Interview on 7 January 2008 with Jamaliah Kario, Senior Transplant Coordinator, National Transplant Resource Centre, Kuala Lumpur General Hospital, Malaysia.

⁴⁴⁸ *Ibid*

⁴⁴⁹ *Ibid*

3.4 PROBLEMS AND CHALLENGES IN PROMOTING ORGAN DONATION IN MALAYSIA

Promoting organ donation and transplantation is not an easy task. Many problems and challenges are faced socially and legally, and also from the religious perspective. One puzzling social challenge that remains unanswerable to this day is how to reduce the gap between the numbers of people registering as organ donors and the low number of actual organs harvested. NTR continuously report small numbers of actual donations each year. For example, there were only 16 actual cadaveric donations in 2004, and the figure dropped to 13 the following year⁴⁵⁰. In both 2006 and 2007, only 25 actual donations took place respectively, although there was an increase in the number of registered potential donors⁴⁵¹. Comparatively, there are about 6000 patients in Malaysia on the waiting list for kidney donations alone⁴⁵². According to Dr. Ghazali Ahmad, this problem is not caused by lack of awareness but by the fact that Malaysians are not ready to become committed actual donors⁴⁵³.

Another social challenge is to deal with objections from family members. According to Lee Lam Thye, Chairman of the Public awareness for Organ Donation Action Committee Malaysia, the current practice is that, once there is any objection from the family, the organ procurement procedure will not proceed even though the donor, during his/her lifetime, had requested the removal of his/her organs⁴⁵⁴. So, even though one has already registered as an organ donor and has received the organ donor card, the potential donor's organs are not removed without the family's consent⁴⁵⁵. That is why it is highly recommended that those willing to become organ donors should, during their lifetime, inform and further convince their family members of their intention to become an organ

⁴⁵⁰ Table 8.1: Number of Procurement by Year, 1997-2007, Lela Yasmin Mansor, Fourth Report of The National Transplant Registry 2007, (NTR Publications, Kuala Lumpur, 2007), p.172

⁴⁵¹ *Ibid*

⁴⁵² Jade Chan, *Organ Donation A Gift of Life*, The Star online, 31 July 2009, <http://www.thestar.com.my>, viewed on 20 October 2010

⁴⁵³ Interview conducted on 12 February 2008 with Dr Ghazali, Consultant and Head Department of Nephrology Department, Kuala Lumpur General Hospital, Malaysia

⁴⁵⁴ Jade Chan, *Organ Donation A Gift of Life*, The Star online, 31 July 2009, <http://www.thestar.com.my>, viewed on 20 October 2010

⁴⁵⁵ *Ibid*

donor. If this could be done, the number of organs harvested would definitely increase as the relatives would be prepared and well aware of the deceased's real wishes.

As for the legal challenges faced, immediate action should be taken to clear up all ambiguities found in the Human Tissues Act 1974. Although a new supplementary policy was recently introduced by the Ministry of Health, the policy will not prevail if it is in conflict with any other existing law. Thus, if the content of the policy were incorporated into an amended Act, the force of law would surely be better able to guarantee its effectiveness and efficiency.

Another challenge is to clear up some of the religious misconceptions and misunderstandings existing. Without doubt, most religions, including Islam, Christianity, Hinduism and Buddhism, do allow and support good deeds of donating organs upon the death of a person. However, in Malaysia, where Islam is the main religion, there are still some misconceptions. The Islamic Understanding Foundation of Malaysia had conducted some research earlier on 500 Muslim respondents about their willingness to become donors, and this indicated that 56.3% of them were not willing to do so. Among the reasons for their refusal was the misconception that, by donating organs, they will later be resurrected as incomplete persons, the procedure will hurt the deceased body, and doctors would not take initiatives to save their lives in emergency situations⁴⁵⁶. Some have the fear that these transplant procedures would delay their burial ceremony while there are also some who think that all transplantation costs involved in the organ removal will burden their families.

The Ministry of Health shoulders the responsibility for ensuring that all donation and transplantation procedures remain safe and beneficial for both donor and recipient. The medical transplantation team must be able to neutralise the 'tissue immunity' reaction so that the recipient's body does not reject the organ received from the donor. The team must also ensure that the donated organs are perfectly healthy without any infections or signs of AIDS, cancer and other diseases. Preserving the organs procured, especially

⁴⁵⁶ Institute of Islamic Understanding Malaysia, (2006) *VISI*, Issue 61-Jan, p.18

during the intervening period between their becoming available and their reception, is also essential to ensure their ability and functions.

Another challenge for Malaysia in general is to provide adequate and affordable facilities to assist all procurement and transplantation procedures to take place locally. All hospitals from the government and private sector must work together hand in hand to make available better facilities complete with new technologies and expertise and to allow the proper selection of organs in order to cater for the number of transplantations needed without having to move the procedure elsewhere. Since the pre-operation, actual operation and post-operation costs are high, another challenge is to ensure that everybody has an equal opportunity to seek treatment since, in most cases, the financial cost required for a transplant procedure is considered a burden, particularly if it is done at a private hospital. The current, normal practice is to resort to the media to seek funding from the generosity of the public. A certain effort must be made to ensure that affordable local treatment, particularly treatment provided at government hospitals, is available and can benefit all Malaysians without any financial limitations and time constraints. One way to reduce the cost is to provide local expertise and facilities. Steps should also be taken to ensure that all funding received is utilised properly and not misused. It is indeed heartening to know that the Malaysian Medical Association has already set up a Medical Advisory Committee to assist in the assessment of those needing this type of treatment and medical care.

3.5 CONCLUSION

Although organ transplantation and donation is taken seriously by the Ministry of Health of Malaysia, there is still a tough task ahead to further increase and boost the number of organ donors. The number of patients in need of vital organs keeps increasing in contrast to the slow rise in those willing to contribute organs and help save more lives. The introduction of the National Organ, Tissue and Cell Transplantation Policy is a great

relief; however, it must be borne in mind that it is only supplementary in nature and does not have any legal powers. Thus, it is recommended that some of these principles be incorporated into the amended version of the Human Tissues Act 1974 to ensure its authority. Lastly, regardless of the situation, the challenge to reduce organ shortage is now becoming more serious in Malaysia. This requires an effective action plan which could increase the number of organ procurements done locally.

CHAPTER 4

ANALYSIS OF EMPIRICAL DATA ON THE ORGAN SHORTAGE PROBLEM IN MALAYSIA

INTRODUCTION

This chapter will set out the details and results obtained from an empirical study relating to organ shortage problems in Malaysia; it was conducted in the Klang Valleys, specifically in Kuala Lumpur and the district of Hulu Langat from December 2007 until February 2008. 482 respondents from the public were involved and they were chosen randomly, though with certain criteria applicable. Results from the study generally reflect the Malaysians' perspective on organ shortage issues. Results from this study will also be used throughout the whole thesis wherever suitable.

4.1 BACKGROUND OF THE STUDY

The Klang Valley location was chosen because most of the people residing there are from different parts of the country. There are a few public institutions of higher education including the National University, University Putra Malaysia, University Malaya and a few other private colleges which cater for students from all over the country. The Klang Valley is also a popular location where local citizens migrate to, as there are a lot of job opportunities available there both in the government and private sector. All these factors contribute to make it the best location to encounter a mixture of respondents from all the 14 states of Malaysia.

Initially, a total of 500 self-administered questionnaires were distributed at random to respondents qualified within the inclusion criteria of being Malaysian, of sound mind, literate and aged 18 years and above. The respondents were approached personally or in groups. Before the questionnaire was distributed, the respondents were asked for their consent to be involved in the study. The purpose and consequences of the study were also explained to them. Most of the respondents were from local universities and hospitals. A lot of the questionnaires were distributed during organ donation campaigns organized by

the National Transplant Registry (NTR) in collaboration with the National Blood Bank. Unfortunately, it is very rare for organ donation campaigns to be carried out independently by NTR as, according to them, it normally does not attract a crowd. That is why NTR will normally join blood donation campaigns as part of their effort to recruit more registered potential organ donors. Another advantage of distributing the questionnaires during these campaigns is that there is a higher probability of some registered organ donors answering the questionnaires as, typically, registered organ donors are keener to donate blood compared to non-organ donors.

At the end of the study, 482 completed questionnaires were collected and analysed. The response rate was very good, at 96.4%. The fact that the researcher was willing to wait for the questionnaires while they were being completed helped to ensure a high response rate. However, this did not affect the answers given by the respondents, because the researcher did not interfere with this process at all and waited from a distance. The remaining 18 completed questionnaires had to be excluded as five were invalid due to locality factors. Here, five Indonesians, whose physical appearances are very similar to Malaysians, had mistakenly taken part in answering the questionnaire. Their responses were rejected and considered void. The remaining 13 questionnaires were not returned to the researcher at all.

4.2 OBJECTIVES OF THE STUDY

This study was carried out with a few particular objectives.

- i) To identify the percentage of potential organ donors among the population of Klang Valley, Malaysia.
- ii) To identify the factors that influence Malaysians to become organ donors and factors that make them reluctant to do so.
- iii) To identify and tackle other related organ transplantation issues including the current registration system, the law regulating the practice and incentives provided for it.
- iv) To discover preferences for the suggested methods of increasing the number of actual organ donors and improve the existing organ procurement procedures available.
- v) To suggest a practical solution for organ shortage problems in Malaysia that might

be developed and suggested for implementation in the future.

4.3 MATERIAL AND METHOD

A questionnaire was distributed to Malaysian citizens chosen randomly, within the age range of 18 to 60. The self-administered questionnaire consisted of five parts including:

- i) Demographic information
- ii) General knowledge
- iii) Registered organ donors section
- iv) Unregistered organ donors section
- v) Solutions suggested.

Part A of the questionnaire contained six questions seeking demographic information from the respondents. They were asked about their age, gender, race, religion, educational level and their state of origin.

Part B focused on the respondents' general knowledge on organ transplantation. They were asked about their source of information on transplantation matters and whether they knew the sources from which human organs were taken. Their preference for being either a living or a cadaver donor was sought besides assessing their knowledge on the problem of organ shortage in Malaysia. The last question in this part sought their awareness on the Human Tissues Act 1974 which currently regulates organ transplant activities in Malaysia.

Part C of the questionnaire was further divided into 2 sections. Section A was to be answered by registered organ donors and Section B was for non-organ donors. In Section A, the registered organ donor respondents were asked how long they had been registered as organ donors and the reasons why they decided to perform such a noble act. They had to disclose whether their intention to donate organs was actually influenced by anybody, whether they had informed their family about it and whether they received full support from their family in doing so. Alternatively, in Section B, the non-organ donor respondents were asked whether they had intentions to become organ donors and what

factors were stopping them from being organ donors. The questionnaire was also designed to ascertain whether anybody had influenced their decision not to register as an organ donor. Their awareness of the registration procedures and the factors that might change their decision to become organ donors in the future were also included.

Part D of the questionnaire was to be answered by all the respondents, both organ donors and non-organ donors alike. This part intended to seek the respondents' preferences for some suggestions put forward. Initially, they were asked whether they had driving licenses. Next, a scenario was given imagining that they had been involved in a serious road accident, had been badly injured and had no chance of survival at all. With this situation in mind, they had to decide whether they would allow the government to automatically assume the authority to take their organs. The next question was related to the same scenario but sought to establish whether they felt that consent from their close family members should be obtained first before the government proceeded to take their organs or, alternatively, whether it could still be done even without family consent being obtained earlier.

The next issue raised was on media publicity. The respondents were asked for their preference regarding media publicity for organ donors. Receiving incentives for organ donation was another issue brought forward. Respondents were asked for their opinion on whether they preferred incentives to be provided and, if so, what form they should take. The options proposed were money and valuables, tax exemption, free medical treatment and others.

The questionnaire also sought to determine whether the respondents agreed with the situation that objections from close family members should be allowed to override an individual's decision to donate organs. And lastly, their opinion was sought on whether they preferred the existing 'opting in' system, where potential organ donors would voluntarily register themselves as organ donors, or whether it should be changed to the 'opting out' system where a person is automatically considered a registered organ donor unless he/she disagrees and formally opts out of the register. The response options

provided were either a 'yes', 'no' or 'unsure'. Finally, all the respondents' answers were entered onto a database, and were analysed statistically using the software programme SPSS for Windows.

4.4 RESULTS OF THE STUDY

i) Demographic factors

A total of 482 respondents had participated by answering the questionnaires distributed. This number included 166 male respondents, which represents 34.4%, while the remaining 316 respondents were females, representing the other 65.6%. Most of the respondents were female university students because there are more female students than males in universities all over Malaysia⁴⁵⁷. The fact that most of the organ and blood donation campaigns were held at universities obviously resulted in more female respondents participating in the study.

This study was limited to people aged between 18 and 60. This specification was made based on section 4 of the Age of Majority Act 1971, which stipulates that the age of majority in Malaysia is 18 years. Therefore, only those aged 18 and above are allowed to make their own decision and give their valid consent to donate organs. Those under that age will need permission and authorisation from their respective parents or guardians. The maximum age limit was fixed at 60 as, presumably, one's organs are still functioning well and are suitable for organ donation purposes until this age. For easy analysis, the age factor was categorised into 5 groups. The first group comprised the 18 to 25-year-olds, as this is the standard age for university students. The second group ranged from 26 to 35 years old. The third group was between 36 and 45 years old and the fourth group was from 46 to 55 years old. The last group comprised all those aged between 56 and 60 and

⁴⁵⁷ According to statistics from the Ministry of Higher Education Malaysia, every year female students outnumber male students in admission to its 20 Institutions of Higher Education all over the country. For the 2008/2009 session, 70,941 new students had registered at these higher education institutions of which 64.5% are female students and the remaining 35.5% are male students. This makes the proportion of female students to male students 60:40.

obviously represents the pensioners⁴⁵⁸ group. The table below clearly shows the results obtained according to the age groupings mentioned above.

Respondents Age Group

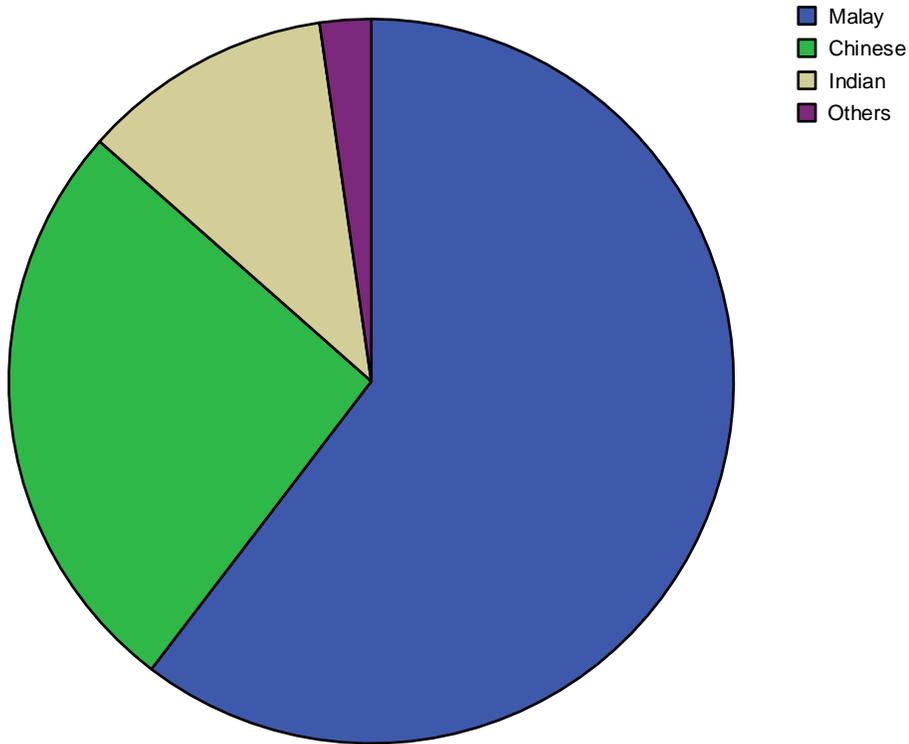
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	18-25	410	85.1	85.1	85.1
	26-35	41	8.5	8.5	93.6
	36-45	19	3.9	3.9	97.5
	46-55	10	2.1	2.1	99.6
	56-60	2	.4	.4	100.0
	Total	482	100.0	100.0	

Based on the table, a majority of 410 respondents are from the first group aged between 18 and 25. This represents 85.1% of the total number of respondents involved. The fact that the study was mostly conducted in local universities had obviously influenced this result as most of the respondents are university students and would logically be within this age group. The next-largest group was the second group where 41 respondents aged between 26 and 35 had taken part in the study. This group made up 8.5% of the respondents. The third group, which had an age range of 36-45 years contained 19 respondents, equivalent to 3.9%. Respondents within the fourth group amounted to only 10, which represented another 2.1%. The smallest was the fifth group, aged 56-60 years, where only 2 respondents (0.4%) were involved in the study.

Malaysia is a multiracial country comprising several different races. The majority race is Malay, followed by Chinese, Indians and other minority races including Kadazans, Ibans, Dayaks and others. The questionnaires were also distributed based on this proportion. The pie chart below illustrates the proportions of the races mentioned above.

⁴⁵⁸ When the study was conducted, the pension age in Malaysia was 56 years, but after the change made in the *Pekeliling Perkhidmatan Bilangan 6 tahun 2008 (JPA/PEN.228/25/1/Jld 4)*, the age limit was increased to 58 years of age, applicable to all public servants

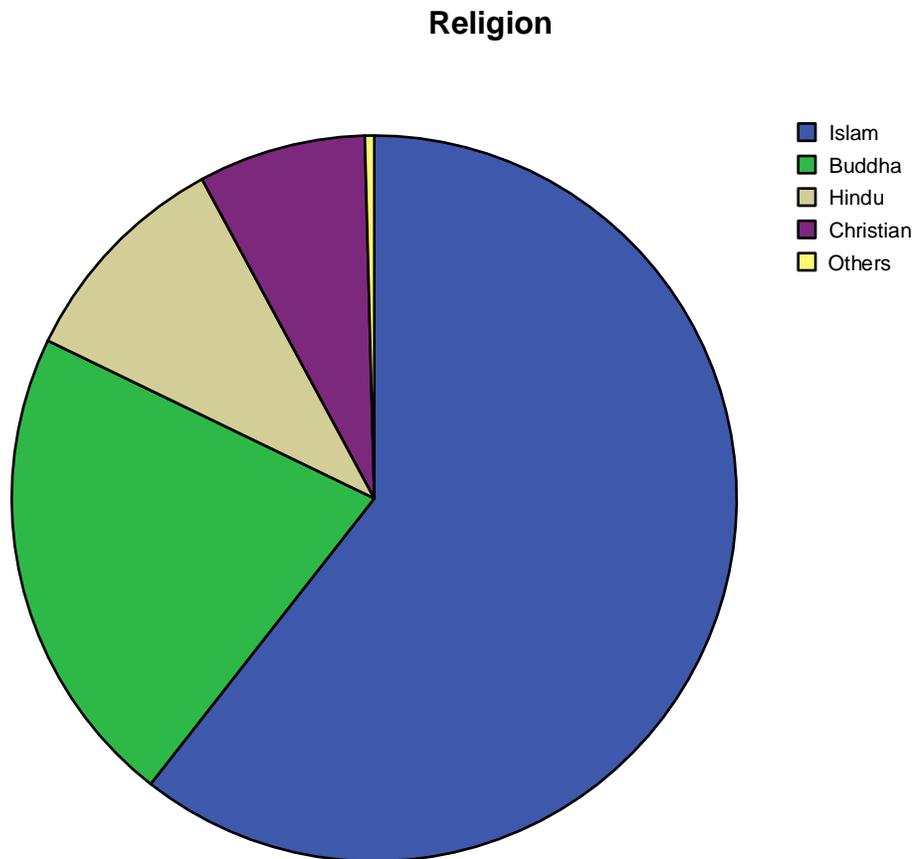
Race



From the pie chart above, it can be clearly seen that a large number of Malays, 291 representing 60.4%, had voluntarily taken part in this study. This is followed by 126 Chinese respondents representing 26.1%, and 54 Indian respondents representing another 11.2%. The remaining 2.3% is represented by the remaining 11 respondents from among the other different minority races stated earlier.

Being a multiracial country, Malaysia gives freedom to its people to profess and practise their own desired religion. However, as the majority of the people are Malays, obviously the main religion would be Islam. Most of the Chinese people profess Buddhism and the Indians are usually Hindus. However, there are also Chinese, Indians and those of other races who are Christians.

Bearing the above fact in mind, the study managed to include 292 Muslims, representing 60.6% of the total. There were 104 (21.6%) Buddhists and 48 respondents (10.0%) were Hindus. About 36 Christian respondents (7.5%) and 2 respondents (0.4%) professing other religions had also taken part in the study. These proportions are clearly illustrated in the pie chart below.



The study classified the number of organ donors and non-organ donors involved in the study according to their religion. From the table below, it can be seen that, from a total of 292 Muslims who took part in the study, 282 respondents (96.6%) were non-organ donors and only 10 were registered organ donors (3.4%). Respondents professing the Buddhist religion amounted to 104, comprising 97 non-donors (93.3%) and 7 registered organ donors (6.7%). As for the Hindus, a total of 48 respondents were involved, of whom 36 were non-organ donors (75%) and the remaining 12 were registered organ donors (25%). There were 36 Christian respondents, of whom 25 were non-donors (69.4%) while the remaining 11 (30.6%) were organ donors. Lastly, adherents of other religions amounted to only 2 and both were non-organ donors.

POPULATION BASED ON RELIGION

		Registered Organ Donor		Total
		No	Yes	
Islam	Count	282	10	292
	% within Religion	96.6%	3.4%	100.0%
Buddha	Count	97	7	104
	% within Religion	93.3%	6.7%	100.0%
Hindu	Count	36	12	48
	% within Religion	75.0%	25.0%	100.0%
Christian	Count	25	11	36
	% within Religion	69.4%	30.6%	100.0%
Others	Count	2	0	2
	% within Religion	100.0%	.0%	100.0%
Total	Count	442	40	482
	% within Religion	91.7%	8.3%	100.0%

The educational levels of the respondents were also classified. A vast majority of 452 respondents had a college or university level of education. This is obviously influenced by the fact that this study was carried out mostly at universities where the blood campaigns were held. Thus, logically, most of them would have this level of educational background. This number represented 93.8% of the total respondents approached. Only

29 respondents had a secondary school-level educational background, equivalent to 6.0% and, lastly, only 1 person (0.2%) had a primary school-level educational background.

ii) General Knowledge

As organ transplantation procedures have been practised in Malaysia for quite some time, the study wanted to reveal whether these respondents are aware and have knowledge on issues related to organ transplantation and organ shortage. From the results, it can be seen that, positively, 98.1% of the respondents are aware of the organ transplantation activity going on. Unfortunately, there are still 9 respondents, representing the remaining 1.9%, who claim to have no knowledge at all on the subject.

The respondents were asked whether they knew the sources from where human organs are retrieved. 3.3% (16 respondents) answered that they come only from living donors, while 12.2% (59 respondents) believed that they could only come from dead donors. A majority of 84.4% (407 respondents) had the correct information that human organs could be retrieved from both living and dead donors.

However, when asked about the circumstances under which they would prefer to donate their own organs, 45.0% preferred them to be taken after death. This percentage represents 217 respondents. Only 13.5% (65 respondents) preferred to donate organs during their lifetime and 41.5% (200 respondents) accepted the idea of donating their organs both during their lifetime and after their death.

One of the questions was intended to assess the respondents' knowledge of organ shortage problems in Malaysia. Positively, 87.6%, which is equivalent to 422 respondents, are aware of the problem. However, 12.4% (60 respondents) confessed to having absolutely no knowledge of this problem.

The majority of the respondents obtained information about the problem of organ shortage through newspapers and magazines. This group comprised 66.8% (322 respondents), followed by radio and television with another 21.8% (105 respondents),

while the Internet is ranked as their last option, with only 2.7% (13 respondents) citing this as their source of information. Other sources, such as friends, doctors, forums and others represented only 8.7% (42 respondents) from the overall total.

In Malaysia, the most popular methods of disseminating information are newspapers and magazines, as these have been the most influential media since independence. Recently, many organ failure patients have managed to get their required organs through touching stories highlighted in the main daily newspapers and leading magazines. Some of the local newspapers even have special segments such as “Searching for a heart for (name of the intended organ recipient)” and specific segments highlighting stories of very sick patients needing organs urgently⁴⁵⁹. Radio and television are ranked in second place in terms of influence, with the Internet in third. Regarding Internet coverage, although it is now becoming a more popular source of information, not everybody has access to its services nor do they own computers. For those living in more remote areas, the Internet service is normally limited, considered quite expensive and is a luxury rather than a necessity.

Regarding the respondents’ knowledge on the sole Act available governing organ transplantation activities in Malaysia, 73.4%, which represents 354 respondents, were totally unaware of the Human Tissues Act 1974. However, at least 26.6% (128 respondents) had knowledge of the existence of this Act regulating the whole subject area.

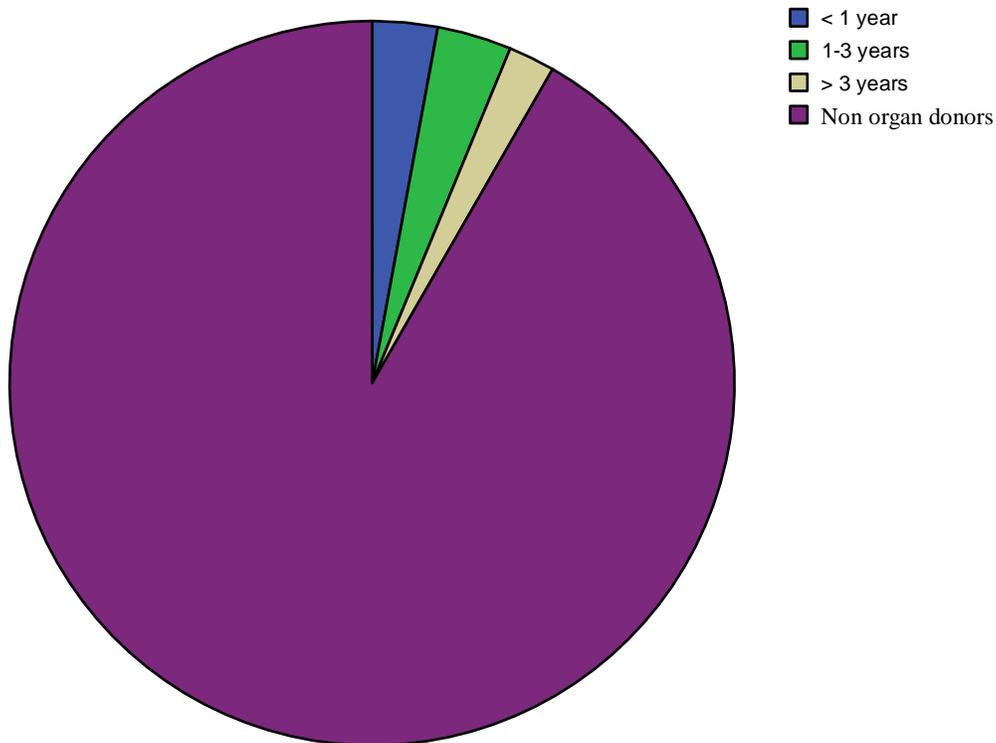
iii) Registered donors

The third part of the questionnaire focused on registered organ donors only. Therefore, only respondents who had already registered themselves as potential organ donors were required to answer this part. The study managed to categorize 40 respondents within this

⁴⁵⁹ For example, one of the local newspapers in Malaysia, Utusan Malaysia, had initiated a campaign searching for a heart donor for Tee Hui Yee from 8 October 2007 and a campaign searching for a lung donor for Siti Salmah Jasni from 18 October 2007. Both campaigns were successful in finding a suitable organ donor for both patients respectively, within just a few days, after massive coverage on the issue was made to the public.

group. This represented 8.3% of the total number of respondents involved in the study. Further analysis of these respondents showed that 14 respondents (35.0%) had just recently registered as potential organ donors, another 16 respondents (40.0%) had been registered for more than a year but for less than 3 years; lastly, only 10 respondents (25.0%) had been registered potential organ donors for more than 3 years. Two persons claimed to have been registered organ donors for the past 9 years, which is the longest duration found within this group of respondents. These findings are clearly illustrated in the pie chart below. The missing portion represents non-registered organ donors who had participated in this study too.

Duration being a registered organ donor



The study also revealed that the main reason influencing 37 respondents (which represents a majority of 92.5%) to become registered organ donors was the spirit of wanting to help save others' precious lives. The remaining 3 respondents (7.5%) had

experience of working with patients in need of organs and this was the motivating factor for their commitment to register as donors. Nobody made such a decision on the basis of having experience dealing with family members needing organs or their expectations of receiving appreciation and incentives.

Another surprising fact was that none of the respondents was influenced by anybody when they made their big decision to become an organ donor. All 40 respondents claimed that nobody had influenced their decision and they had made the decision on their own. This amounted to a full 100% result.

Informing family members of our intention to donate organs is crucial. In this study, a majority of 34 respondents (85.0%) from the registered organ donor group had informed their family about this matter. However, the remaining 6 respondents, who represented 15.0%, had simply kept the matter to themselves and had not mentioned anything at all to their families about their decision. However, the response received from their family members did differ. Not everybody received full support for their noble intention to donate organs as only 60.0%, which is equivalent to 24 respondents, had fortunately obtained this. The remaining 16 respondents (40.0%) faced family opposition to their decision. In contrast to the above findings, while 6 respondents had not revealed their decision to register as potential organ donors, 16 respondents claimed that they had not received family support in doing so. This may be because some of the respondents already knew their family's stand, which was not in favour of organ donation. Thus, even without asking directly, they would have been able to assume and predict their family's attitude and response even before raising the matter and seeking their consent.

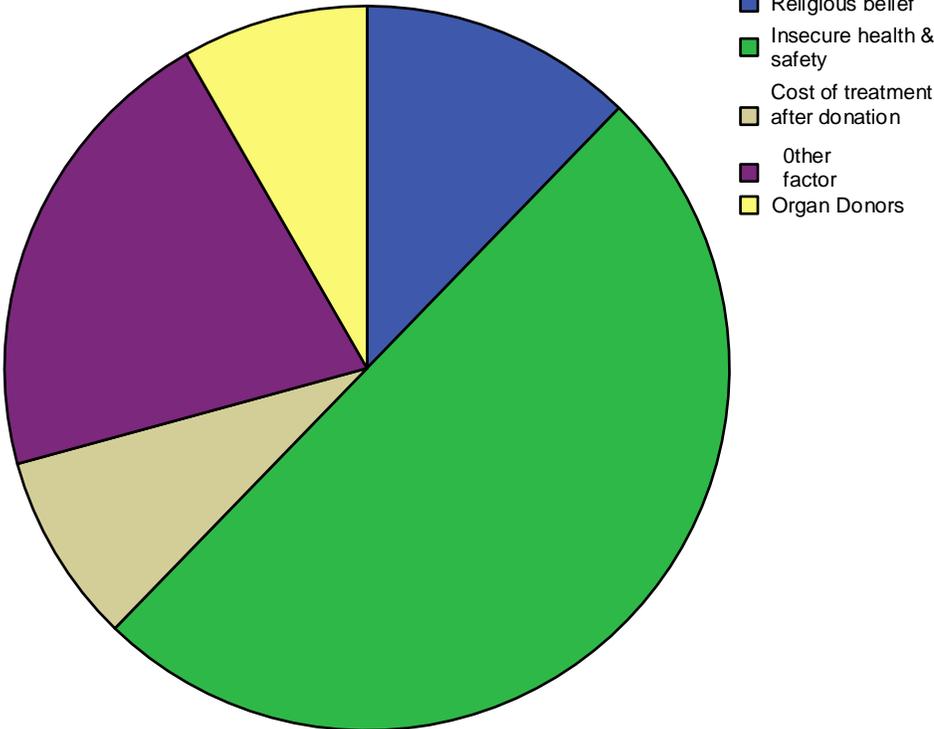
iv) Non-donors

The fourth part of the questionnaire was addressed to respondents who were non-registered organ donors. In total, 442 respondents answered this part. The respondents were asked whether they had ever had the intention of donating their organs. The result was that 237 respondents (53.6%) declared that they had no intention at all of becoming

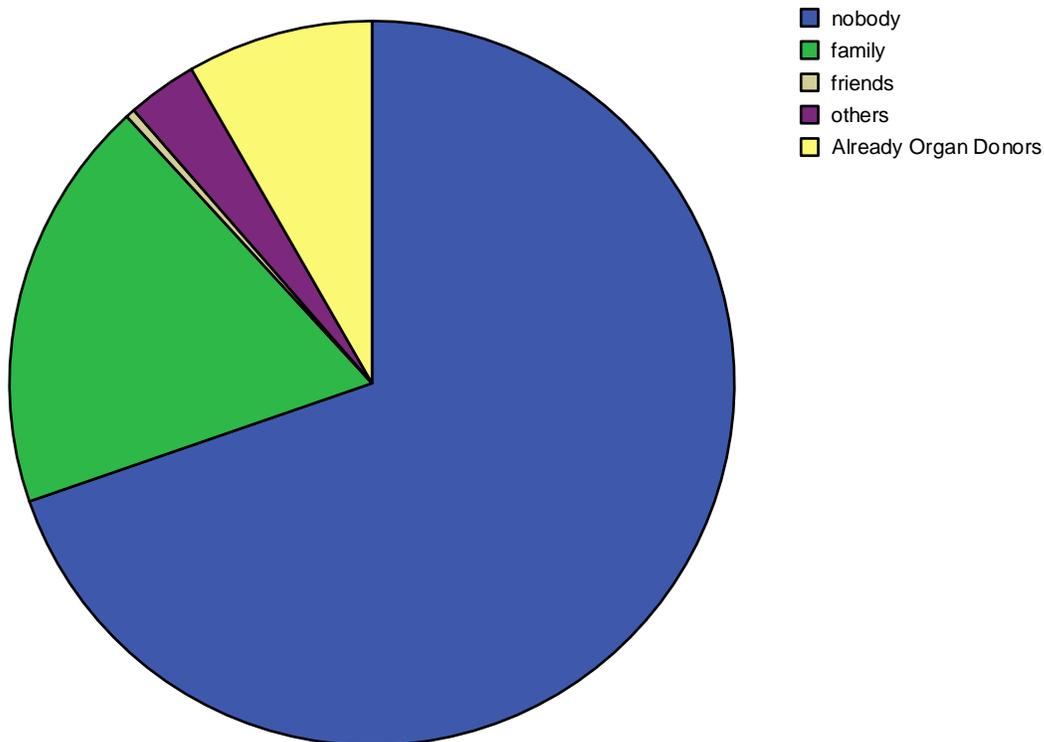
organ donors, while 46.4% (which covers the remaining 205 respondents) did have the intention to register themselves as organ donors although they had not yet done so.

The study also tried to identify factors stopping all the 442 respondents from registering as organ donors. Surprisingly, the most significant factor was that they were not confident and had doubts over their health and welfare during and after the transplant procedures. A large number of 241 respondents, which is equivalent to 54.5%, claimed this factor to be their main obstacle. 59 respondents, amounting to 13.3% of the respondents, were not clear about their religion's stand on organ transplantation matters, causing them to feel reluctant to become an organ donor, while another 41 respondents (9.3%) claimed that fear of having to bear the treatment costs after the donation procedures was their main reason for refusal. The remaining 22.9% (101 respondents) had other personal reasons such as being forbidden by family members, having health problems, not being mentally prepared, lack of awareness, lack of information on organ transplantation matters, lack of support and motivation, and having fear of operations and hospital procedures. These factors are clearly grouped and presented in the pie chart below.

Factors Influencing Non-Donors

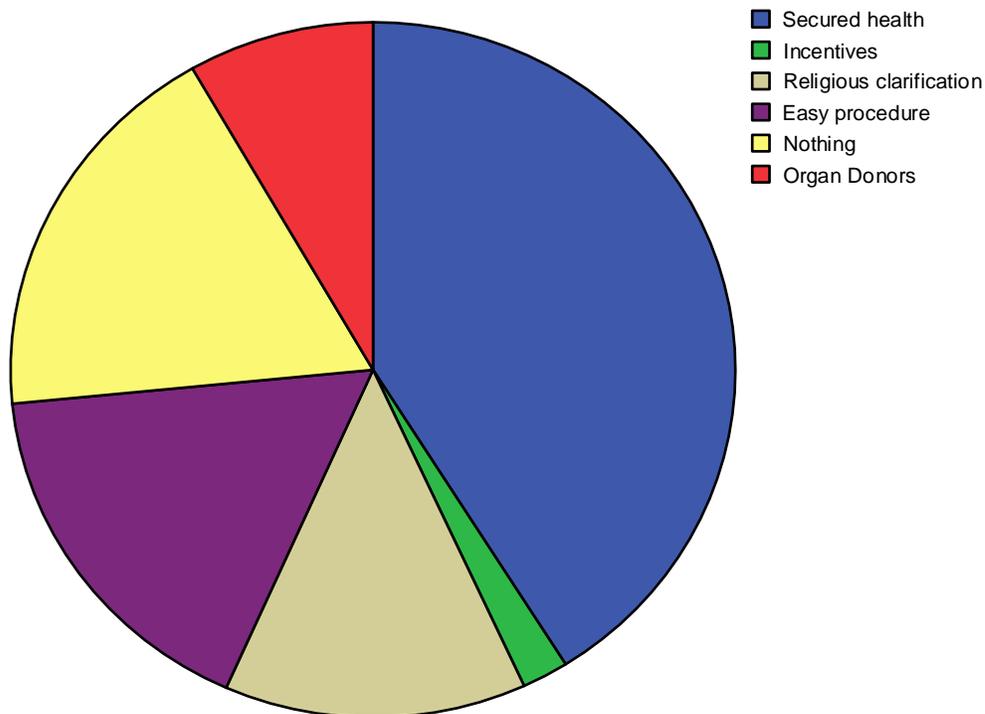


Influence of others towards non-donors



With regard to the influence of other people on their decision not to become organ donors, a huge majority of 336 respondents, which represented 76.0%, were not influenced by anyone at all. So, their decision was initiated purely by themselves. Only 89 respondents (18.5%) claimed to be influenced by their family, and a small percentage of 0.5% (2 respondents) was influenced by their friends. The remaining 15 respondents (3.1%) claimed to be influenced by people other than their families and friends in deciding not to become organ donors. The pie chart above presents this discussion.

Factors that might influence non-organ donors to become organ donors



The pie chart above illustrates different factors that might influence non-organ donor respondents to become organ donors in the future. In the study, 198 respondents (representing 44.8%) felt that, if assurance on their safety and health concerns could be guaranteed, they were willing to change their minds and become registered organ donors in the future. 16.8% (81 respondents) demanded that an easier registration procedure be made available, while 14.7% (65 respondents) cited clarification of their religions' stands as the main factor that might change their decision to become organ donors. Surprisingly, only 2.1% (10 respondents) considered incentives as a promoting factor that could change their decision. Unfortunately, 18.3% (88 respondents) were steadfast in their decision not to become organ donors. They firmly claimed that nothing at all would change their decision.

Regarding awareness of the organ donor registration procedures, a majority of 358 respondents claimed that they were totally unaware of them. This formed a high

percentage of 81.0%. In contrast, only 84 respondents (17.4%) knew about the procedures applicable in registering as a potential organ donor.

v) Solutions

Possessing Valid Driving Licenses

			Driving License		Total
			No	Yes	
Respondents	Non Donor	Count	105	337	442
		% within Non Registered Donor	23.8%	76.2%	100.0%
	Organ Donor	Count	5	35	40
		% within Registered Donor	12.5%	87.5%	100.0%
		Count			
	Total	% within Total Respondents	110	372	482
			22.8%	77.2%	100.0%

This last part of the questionnaire was intended to discover the respondents' perceptions of a few suggestions that could be practically applied in Malaysia. The first question in this part inquired whether they possessed a valid driving license. From the table above, it can be seen that, among the 442 non-registered organ donors, 337 respondents (76.2%) had a driving license while the remaining 105 respondents (23.8%) did not. As for the registered organ donors group, from a total of 40 respondents 35 (87.5%) had driving licenses and the remaining 5 respondents (12.5%) did not. So, combining both groups, from a large total of 482 respondents, 77.2% possessed driving licenses and only 22.8% did not.

Consenting to the Government Acquiring Organs

			Consent to Government		Total
			No	Yes	
Organ Donor	No	Count	211	231	442
		% within Non Registered Donor	47.7%	52.3%	100.0%
	Yes	Count	3	37	40
		% within Registered Donor	7.5%	92.5%	100.0%
Total		Count	214	268	482
		% within Total Respondents	44.4%	55.6%	100.0%

The next question sought to discover the respondents' willingness to allow the government of Malaysia to acquire their organs should they suffer a serious road traffic accident with no chance of survival at all. Positively, a total of 268 respondents (55.6%) from the total of 482 respondents agreed to this idea; however, the remaining 214 respondents (44.4%) disagreed with this notion. To further classify the details within the two different groups involved, within the non-registered organ donor group, a total of 231 respondents (52.3%) agreed with this suggestion, so the remaining 211 (47.7%) were against it. Within the registered organ donor group, a majority of 37 respondents (92.5%) agreed with this notion while only 3 (7.5%) disagreed with it.

Next, the respondents were asked to state whether, in the same situation above, if by any chance the government were allowed to procure their organs, they would prefer their family members to be consulted on their behalf or whether family consent need not be acquired at all. Surprisingly, a large majority of 88.0% (representing 424 respondents) wanted their family to be consulted first and considered their consent necessary. Only 58 respondents (12.0%) opined that family consent was not necessary and agreed that their organs could be retrieved by the government automatically if the need arose. Within the non-donor group, a large majority of 394 respondents (89.1%) insisted on having family consent first and only 48 respondents (10.9%) felt otherwise. As for the registered organ donor group, 30 respondents (75%) opined that family consent was needed, although the

remaining 10 respondents (25.0%) took the opposite view. The table below clearly shows the figures as discussed above.

Family Consent

		Consent Family		Total
		no	yes	
Organ Donor	Non Organ Donor	Count 48	394	442
		% within Non Registered Donor 10.9%	89.1%	100.0%
Organ Donor	Organ Donor	Count 10	30	40
		% within Registered Donor 25.0%	75.0%	100.0%
Total		Count 58	424	482
		% within Total Respondents 12.0%	88.0%	100.0%

Regarding media publicity, the respondents' views were almost equally split, as 250 respondents (equivalent to 51.9%) favoured media publicity for their willingness to donate organs. On the other hand, 232 respondents (representing the remaining 48.1%) preferred their noble act of donating organs to remain without media publicity. Even when this group of respondents was further divided into the non-registered donor group and the registered donor group, the end result was quite similar as both groups tended to be divided almost equally in their preference for having media publicity involved or not. So, in conclusion, regardless of whether a person is an organ donor or not, their preference regarding media publicity is not affected. The table below clearly shows the results obtained.

Media Publicity

		Media Publicity Required		Total	
		no	yes		
Organ Donor	No	Count	212	230	442
		% within Non Registered Donor	48.0%	52.0%	100.0%
Organ Donor	Yes	Count	20	20	40
		% within Registered Donor	50.0%	50.0%	100.0%
Total		Count	232	250	482
		% within Total Respondents	48.1%	51.9%	100.0%

On the suggestion to provide rewards to organ donors, an overall figure of 274 respondents (56.8%) agreed and supported this notion; however, 43.2% (which covers 208 respondents) disagreed with this. Within the non-registered organ donor group, 260 respondents (58.8%) supported the idea of incentives, though the remaining 182 respondents (41.2%) were against it. As for the registered organ donor group there was a high percentage of 65.0%, representing 26 donors, who felt that incentives were not necessary. Only 14 respondents (35.0%) in this group agreed with the idea of providing incentives. The figures are shown in the table below

Rewards and Incentives

		Reward/ Incentives		Total
		No	Yes	
Organ Donor	Count	182	260	442
	% within Non			
	Registered	41.2%	58.8%	100.0%
	Donor			
	Count	26	14	40
	% within			
Yes	Registered	65.0%	35.0%	100.0%
	Donor			
	Count	208	274	482
Total	% within Total			
	Respondents	43.2%	56.8%	100.0%

The respondents were also asked about the type of incentive preferred. They had to choose between monetary or valuable gifts, tax exemption, and free treatment and medication. The respondents were also allowed to suggest their own preferred incentives if the options given did not suit them. The study revealed that a majority of 335 respondents (69.5%) preferred to receive free treatment and medication as rewards for their willingness to donate organs. This number comprised 304 respondents within the non-donor group and 31 respondents from the registered organ donor group.

Monetary or valuable gifts were preferred by only 81 respondents (equivalent to 16.8%). This included 79 respondents within the non-donor group and only 2 respondents from the registered donor group. Incentives in the form of tax exemptions attracted only 33

respondents (16.8%), a figure formed by 32 respondents from the non-donor group and only 1 from the other group. The remaining 33 respondents (16.8%), comprising 27 from the non-donor group and 6 from the donor group, had their own preferences for incentives. Some suggested that the free treatment and medication given should also be extended to cover all their family members too. There were even some respondents who did not want to receive anything at all as an incentive. They stressed that their act of donating organs was done for the sake of helping others and therefore refused to accept any kind of reward offered.

Next, the respondents were asked whether they agreed that their close family members should be given the authority to override their earlier decisions to donate organs, especially when the actual time comes to harvest their donated organs. As predicted, more than half of the respondents, amounting to 54.4% (262 respondents), opined that family objections should not be allowed to alter or change an individual's earlier decision to donate organs. This was represented by 225 respondents (50.9%) from the non-donor group while the remaining 217 respondents (49.1%) from the same group supported the family's right to object.

From the registered donor group, a strong majority of 92.5%, comprising 37 respondents, rejected family interference and objections while only 3 respondents (7.5%) were still in favour of it. So, the overall percentage of respondents still supporting family objections was 45.6%, representing 220 respondents. The figures mentioned above are clearly laid out in the table below.

Family Objection

			Family Objection		Total
			no	yes	
Organ Donor	No	Count	225	217	442
		% within Non Registered Donor	50.9%	49.1%	100.0%
	Yes	Count	37	3	40
		% within Registered Donor	92.5%	7.5%	100.0%
		Count	262	220	482
	Total	% within Total Respondents	54.4%	45.6%	100.0%

Finally, the study sought the perceptions of the respondents on the suggestion of changing the existing ‘opting in’ system to the ‘opting out’ system. Surprisingly, there was quite an even outcome which was further categorized into three different perceptions. 37.3% (180 respondents) rejected the opting out system suggested, 35.7% (172 respondents) clearly accepted the suggested new system and the remaining 27.0 % (130 respondents) were confused and unsure whether the existing opting in system should be changed in favour of the opting out system or not. Scrutinizing the figures within the non-organ donor group only, 36.9% (163 respondents) rejected the suggested opting out system, 34.6% (153 respondents) agreed with it and another 28.5% (126 respondents) could not choose between the two systems mentioned.

From the organ donor group, 42.5% (17 respondents) rejected the opting out system, 47.5% (19 respondents) fully supported it and the remaining 10.0% (4 respondents) were unable to choose between the two systems put forward. The table below clearly illustrates the figures mentioned above.

Response to the Opting Out System

		Opting Out			Total	
		No	Yes	Unsure		
Organ Donor	No	Count 163	153	126	442	
		% within Non Registered Donor	36.9%	34.6%	28.5%	100.0%
	Yes	Count 17	19	4	40	
		% within Registered Donor	42.5%	47.5%	10.0%	100.0%
	Total	Count 180	172	130	482	
		% within Total Respondents	37.3%	35.7%	27.0%	100.0%

4.5 DISCUSSION

The study carried out on 482 respondents fortunately included 40 registered organ donors. As expected, a majority of the respondents was aware and had at least basic knowledge on organ donation activities in Malaysia. The study positively proved that 98.1% of the respondents had knowledge about organ donation procedures taking place in Malaysia, although there were still 9 respondents who denied knowing anything about it at all. However, the fact that more than half of the respondents had precise knowledge on organ sources showed that most of them had correct information on this particular issue. The results also showed that Malaysians would prefer to become cadaver donors rather than living ones, or perhaps both. This fact signifies that campaigns and initiatives to recruit more organ donors should focus on maximizing the number of potential cadaver donors. Perhaps the preference shown is due to the minimal risks involved, especially to the donor him/herself, as he/she would no longer be alive, and the fact that, legally, these organs could be donated to a larger selection of recipients rather than being restricted and confined only to close family members.

422 (87.6%) respondents had knowledge of organ shortage problems in Malaysia. This is again a good sign since most of the respondents are young and suitable candidates as potential organ donors. Having knowledge of the seriousness of the problem could develop people's sympathy for those in need and might also open their hearts to become organ donors one day. Normally, people aged between 19 and 59 and equipped with a higher level of education are more positive to the idea of donation compared to teenagers, those aged 60 years and above and people with a lower educational level.⁴⁶⁰ Young and well-educated individuals might have access to knowledge of scientific progress and feel more confident with medical developments than older and less-educated persons, which might be reflected through these attitudes⁴⁶¹. Were they to realise the existence of the problem, it would make it easier to run campaigns encouraging more organ donations to take place.

A majority of the respondents stated that their main source of knowledge on organ donation was disseminated from the media rather than from other sources. Local newspapers and magazines were ranked as the most influential medium of knowledge. Electronic media, such as television and radio, were ranked in second place. This might be due to the fact that not as much publicity on organ transplantation is broadcast through these channels compared to the written media. Although the use of the Internet is now becoming more popular, especially among adolescents and young adults, it was not nominated as their main source of information on organ transplantation matters. The underlying reason might be that they did not use it to search for organ donation issues. Comparatively speaking, in newspapers and magazines, these issues are presented in a more straightforward manner to them, whereas seeking information through the Internet would require the user to specifically search for a particular issue. Thus, if one did not have interest in a particular matter, one would not search for it through the Internet. Perhaps this fact influenced them to state their preference for newspapers and magazines rather than the radio, television and Internet facilities as their main source of knowledge on organ donation. A survey conducted in Turkey among influential religious people

⁴⁶⁰ Margareta, A. Sanner, 'People's Attitude and Reactions to Organ Donation' (May 2006), Vol. 11, No.2 *Mortality*. 135-136

⁴⁶¹ *Ibid.*

clearly proved that transplantation issues are normally discovered and learnt through the media rather than any other method although, unfortunately, it did not specify which media were most influential⁴⁶².

The result of the study also suggests that the authority of the Human Tissues Act 1974, which regulates human organ transplantation matters in Malaysia, has not been sufficiently acknowledged by the public. Since the rule “ignorance of the law is not an excuse” does apply, a more serious effort must be made to ensure that Malaysians are made aware of and realise the application of this Act which governs and regulates these matters, although it might not be totally comprehensive in nature and content. Sadly, the study revealed that only 128 respondents knew about it and most of these had legal backgrounds.

Among the registered organ donor group, not everybody had informed their families about their decision to become an organ donor. The results showed that, although 85% did inform their families, a remaining 15% chose to keep their decision to themselves, which is still a high percentage. Within this group too, only 60% (24 respondents) received support from their family while the remaining 16 respondents faced objections. This high percentage needs to be taken seriously, as family objection is acknowledged according to Malaysian Law. Not informing family members of one’s intention to donate organs is similar to leaving the final say to the family. This might consequently lead to fewer organs being donated as there are various reactions concerning the dead body, particularly from family members. Having thoughts of allowing the dead body to experience discomfort and pain when it is cut, and organs removed from it, makes it a tough decision for the families to make⁴⁶³. The more the person means to them, the harder it is to imagine and accept the experience that the deceased might go through, though he/she is actually no longer alive. Another notion that might deter families from giving consent is the thought that the deceased should be left to rest in peace and that any

⁴⁶² Kececioglu, N, Tuncer,M, Yucetin,L, et al. ‘Attitudes of Religious People in Turkey Regarding Organ Donation and Transplantation’ (2000) 32 *Transplantation Proceedings*, 629

⁴⁶³ Frutos,M.A, Ruiz,P, Requena, M.V, and Daga,D, ‘Family Refusal in Organ Donation : Analysis of Three Patterns’, (2002) 34 *Transplantation Proceedings*, 2513-2514

incision into the body would be disrespectful. These two reactions would mean that what might be done to a dead body should be no more than what might be done to a living individual⁴⁶⁴. Family conflicts and cultural and religious beliefs are additional reasons, besides emotional factors, contributing to families' refusal to consent⁴⁶⁵. It is evident from other surveys that people would be more likely to decline to donate organs from their next of kin than from themselves. For example, in Sweden, although about two-thirds of the adult population favours donation, only about 40% would consent to allow donation from a relative. Most would claim they did not know what to decide on behalf of the deceased and were afraid of making the wrong decision. So, normally, the number of donors would be lower if the relatives had to decide than if the deceased had actually expressed a prior wish of his/her own⁴⁶⁶.

Without doubt, the deceased's expression in life of his/her wishes about donation would definitely be the most predictive factor in the family's decision⁴⁶⁷. This means that, when the wishes of the deceased are known, the family's decision is typically consistent with it and could even reach a consent rate of 95% to 100%⁴⁶⁸. In contrast, when the deceased's prior wishes about donation are unknown the family's decision will normally be largely influenced by contextual and intrapersonal factors⁴⁶⁹. It is suggested that organ donation matters should be made a more common issue for discussion. This would perhaps make it easier to bring up the matter, especially within family conversations. Organ donors should be counseled on the best approach for them to break the news and inform their families of their decision. Counseling for family members would also be beneficial as explanation from experts in the field could obviously remove all doubts and anxiety in

⁴⁶⁴ Margareta, A. Sanner, 'People's Attitude and Reactions to Organ Donation' (May 2006) Vol. 11, No.2 *Mortality*, 140

⁴⁶⁵ W.H.Marks, D.Wagner, T.C. Pearson et al, 'Organ Donation and Utilization in the United States' (2006) *Am.J.Transplant* 6, p.1101.

⁴⁶⁶ Margareta, A. Sanner, 'People's Attitude and Reactions to Organ Donation' (May 2006) Vol. 11, No. 2 *Mortality*, p.140

⁴⁶⁷ Jose M. Martinez, Jorge S. Lopez, Antonio Martin, et al. 'Organ Donation and Family Decision-Making within the Spanish Donation System' (August 2001) *Social Science & Medicine*. Vol.53, Issue 4, 405-421. p.411

⁴⁶⁸ Ojo,A.O, Heinrich,D and Emond,J.C et al. 'Organ Donation and Utilization in the United States' (2004) *Am J Transplant* 4 (2004) (Suppl9).p.24 quoted in Medina-Pestana, J.O, Sampaio, E.M, . Santos,T.H.F, et al. 'Deceased Organ Donation in Brazil: How Can We Improve?' (March 2007) *Transplantation Proceedings*. Vol.39, Issue 2, pp.401-402.

⁴⁶⁹ *Ibid*, p.412

their minds. So, besides disseminating all the facts related to transplantation activities, its legal rules and surgical procedures, an effort should also be made to help families deal with their anxiety, giving them room to seek clarification and feel reassured about the transplantation procedures. Thus, in this matter, support must be provided to both donors and their families to ensure awareness and acceptance of the decision already made.

The respondents in the non-donor group were split in their decision when asked whether it had ever crossed their minds to become organ donors in the future. A percentage of 49.2% admitted to having no intention at all, leaving more than half to give a positive response. The study revealed that the former's reluctance was very much related to their feelings of insecurity. They have not been persuaded to risk their health and safety during and after the transplantation procedures. This shows that there is a lack of confidence in the existing transplant system. However, were this weakness to be overcome, many patients would definitely benefit from the large percentage of respondents who might be interested in registering as potential organ donors. Another survey on attitudes towards organ donation in Sweden demonstrated that more than half of the population surveyed was positive about donating their organs, a large group is undecided and the smallest proportion is negative. The exact percentages of positive, hesitant and negative individuals vary depending on the timing of the survey, specific culture of the society and type of population surveyed⁴⁷⁰. Although the level of percentage might vary depending on these factors, the ranked order of the attitudes is still the same⁴⁷¹. Thus, the findings of this study are consistent with other previous studies. There is a clear challenge to Malaysia to secure consent from those who have pledged to become organ donors, convert the substantial proportion of those who are unsure, and, lastly, convert those who are not in favour of organ donation and persuade them to register as donors.

⁴⁷⁰ Margareta, A. Sanner. 'People's Attitude and Reactions to Organ Donation' (May 2006) Vol. 11, No. 2 . *Mortality*, p.135

⁴⁷¹ Margareta, A. Sanner. 'Giving and Taking - to Whom and from Whom? People's Attitudes Towards Organ Transplantation of Organs and Tissue from Different Sources' (1998) 12 *Clinical Transplantation*, 515-522.

As expected, the study revealed that religion was not the main reason for Malaysians being reluctant to become organ donors. Only 13.3% of the total respondents cited religious factors as their main obstacle. In a local survey conducted previously by the Islamic Understanding Foundation of Malaysia (IKIM) with 500 Muslim respondents, 56.3% were found to be unwilling to become registered organ donors. Their hesitance was based on the perception that they will later be resurrected as incomplete persons; the procurement procedure would hurt the deceased body and it would delay their burial ceremony⁴⁷². Though my findings cannot be wholly compared to this survey, since this study involves respondents from a number of races and religions, the findings are still coherent as, from a total of 292 Muslims involved, only 10 respondents, amounting to a small percentage of 3.4%, are registered organ donors. A huge majority of 96.6% remain as non-organ donors. So, it is evident that Muslims in Malaysia are more reluctant to become organ donors, even when compared to other religious groups such as Hindus, Buddhists and Christians.

In a different study on cadaveric organ donation at the University Hospital Malaysia, a similar finding was obtained, as it again proved that misinterpretation of religious teachings regarding organ transplantation is not the main obstacle, although it is still a contributing factor⁴⁷³. Both local studies quoted are consistent and strongly support the findings of this research. In a different study, which examined the influence of religion on attitudes towards organ donation among the Asian population in Luton, United Kingdom, it was indicated that, within the population studied, culture and religion play a much less prohibitive part in determining the level of organ donation than previously suggested⁴⁷⁴. However, there is a desire to be aware of religious stances so that people are able to make a more informed decision⁴⁷⁵. Again, the findings have proved to be similar in principle, where religion is not the main obstacle to people donating their organs. This might be

⁴⁷² Institute of Islamic Understanding Malaysia, (2006) *VISI*, Issue 61-Jan, p.18

⁴⁷³ Chen, T.P, Teo, S.M, Tan, J.C.K, et al. 'Cadaveric Organ Donation at University Hospital Kuala Lumpur' (2000) *Transplantation Proceedings*. vol. 32, p.1809-1810

⁴⁷⁴ Gurch Randhawa, 'An Exploratory Study Examining the Influence of Religion on Attitudes towards Organ Donation among the Asian Population in Luton, UK' (1998)13 *Nephrol Dial Transplant*, p.1949-1954

⁴⁷⁵ *Ibid.* p.1949

related to the fact that people are now more knowledgeable and comprehend religious stances more clearly. Thus, from all the various results of the studies mentioned above, it could be concluded that religion is no longer the main factor causing the shortage of organs as it might once have been. A detailed discussion of the Islamic perspective on organ donation will be conducted in chapter seven of the thesis. However, other personal factors, including facing family objection, health problems, apprehensive feelings, and lack of information and motivation also contribute, though only as minor factors.

The study also found that a majority of the respondents (81.0%) were unaware of procedures for becoming an organ donor. Some respondents actually wanted to register as potential organ donors but did not know where to turn to. This suggests that, besides having campaigns promoting the matter, the Ministry of Health of Malaysia should also make available an easier, more straightforward system where people could easily register and even deregister themselves if they later changed their minds. The current system requires those interested in becoming organ donors to fill in forms which are distributed at organ donation campaigns or are available at hospitals and the National Transplant Registry office. The form requires personal details such as name, age, address and date of birth to be submitted. The donor can even specify which organs they wish to donate accordingly. Registration online through the NTR website is also available. After registration is completed, the potential organ donor will then receive a small green identification card which they should carry with them at all times. This card is evidence that the bearer is now a registered organ donor. However, although this system is good, it might be worth further extending efforts to make the registration procedures even more user-friendly. In the United Kingdom, for example, organ donation registration forms are distributed even more widely as, in every application to renew driving licenses or road tax certificates, these forms are also included. This indirectly makes people more aware of the possibility of donating organs and allows an individual to revise their decision if they have not decided to register as an organ donor. Online registration is also effective as more people now prefer to do things online rather than in the ordinary manual way.

Most important of all, the study aimed to discover the main factors causing Malaysians to be so reluctant to become organ donors, which subsequently leads to the problem of organ shortage. The study proved that their reluctance was mainly related to their feeling of not being convinced about the transplantation outcome, including having doubts and worries about their health and safety. The study showed that 44.5% were willing to change their minds if they could be assured of their health and safety during and after the transplantation procedures. Although this should not be referred to as guaranteeing life, which is indeed beyond our control as humans, the potential donors must at least be convinced that, with the existing system, all means and efforts have been taken to ensure that the transplant procedures are safe, while all potential risks that might be involved are also minimised as much as possible. It is suggested that assurances about their safety and health should also include close monitoring and follow-ups after the operation procedure which not only focus on their health status but also on their social welfare and quality of life.

Similar findings also resulted from a study within a Turkish community which looked into the public's attitude towards organ donation. It was revealed that the main reasons for refusal were also due to insufficiency of knowledge about transplantation and misinformation regarding the organ donation process⁴⁷⁶. This exactly supports the findings of this study. A different study, conducted with university students in China, showed that 86.9% were worried about death resulting from the surgical donation procedure, 93.1% were worried about a lower post-operative quality of life and, lastly, 93.3% were concerned about post-operative complications⁴⁷⁷. All these are possible negative impacts that might result from each transplant procedure; thus these risks must be minimised to prevent people experiencing fear and reluctance to become organ donors. The researcher believes that these fears are naturally common though they must be dealt with effectively. People must be reassured that these risks can be reduced to a

⁴⁷⁶ Bilgel H, Bilgel N, Okan N, et al. (1991) *Transplant International* 4 :243,

⁴⁷⁷ Zhang,L, .Li,Y, Zhou,J et al. 'Knowledge and Willingness toward Living Organ Donation: A Survey of Three Universities in Changsha, Hunan Province, China' (2007)39 *Transplantation Proceedings*, 1303-1309 p.1306.

very minimal percentage and that their welfare will still be made a priority even after the organ donation procedure has been completed.

The National Transplant Registry of Malaysia (NTR) should work hand in hand with public and private hospitals to disseminate more information and knowledge on the transplant procedure and its outcome since fear and doubts are normally related to insufficient information being received. It is also suggested that organ donation campaigns invite organ recipients to share their personal experience, hopes and expectancies in life. A different study, which assessed the effects of an educational programme about organ donation delivered by ex-patients with a successfully transplanted donor kidney in adolescents, found that the educational programme did encourage adolescents to make a better, well-considered choice with regard to organ donation registration⁴⁷⁸. However, since this feeling of fear and insecurity is more likely in a living organ donor, this indirectly suggests that resorting to cadaver donors is the best alternative. In other words, more action must be directed towards promoting cadaver donors as sources organs, compared to resorting to living donors. This system is not only more practicable but also eliminates the issue of having fear for one's health and safety during and after the transplantation procedures, as the donors involved are non-living ones. The second factor causing their reluctance is the registration system itself which they perceive as limited and not easily accessible. To attract more registered organ donors, an easier and more user-friendly registration system must be made available to the public at large.

Having doubts about religious stances which, according to the respondents, have not been made clearly known to the public, was ranked in third position. It is a fact that people are indeed very sensitive when dealing with religious perceptions; thus, all efforts must be made to clearly set out the stance of each of these religions on organ donation although,

⁴⁷⁸ Marleen Smits, Bart van den Borne, Anton J. Dijker and Richard M. Ryckman. 'Increasing Dutch Adolescents' Willingness to Register their Organ Donation Preference: the Effectiveness of an Education Programme Delivered by Kidney Transplantation Patients'. *The European Journal of Public Health*. Vol. 16, No.1. pp.106-110.

generally, most religions actually allow organ donation procedures to be done for the sake of saving others.

Surprisingly, the least cited factor in the respondents' reluctance to register as organ donors was the absence of incentives and rewards. In this regard, only 10 respondents (2.1%) stated that, were incentives to be provided, they would be interested in becoming organ donors. Providing incentives for organ donation has always been a debatable issue; thus, in this study, the researcher also aimed to reveal what form of incentives would be preferable, were they to be offered in Malaysia one day. All 482 respondents responded to this, and the results showed that 57.7% agreed with it and that it is necessary to give incentives. The remaining respondents rejected this idea.

Five options were suggested to determine what type of incentive was the most preferable. Receiving free medical treatment from government hospitals was the most popular option nominated. Medical treatment here refers to all types of medical procedures including consultation and medication supply. It is not limited just to organ transplantation procedures. This notion was supported by a majority of 314 respondents, representing 68.4% of the total respondents. The second most preferable form of incentive was money or receiving certain valuable rewards. This was supported by 17.2 %, while only 7.2% preferred to have incentives in the form of tax exemptions. The remaining 7.2% suggested the incentive of free medical treatment should be extended to their family members, while a few rejected any incentive in any form at all. They were adamant that organ transplantation is an altruistic act; thus no material reward should be expected from it. The researcher supports the group that favours incentives although personally agrees that organ donation should still be based on altruistic intentions.

Those against the idea of incentives argue that organs are priceless and therefore must not be sold. No amount of money is comparable to any part of the human organs. Besides, donations should emanate from altruistic motives⁴⁷⁹. There is also a possibility that rich,

⁴⁷⁹ Ona, E.T. 'Compensated Living Non-related Organ Donation: An Asian Perspective' (2000) 32 *Transplantation Proceedings*, 1477-1479.

more powerful people will start taking advantage of the poor who desperately need money. Although the above factors are obviously true, the fact that altruism has failed to supply sufficient organs and that the donor faces huge risks from the donation should also be considered. However, the researcher disagrees with the notion that incentives are equivalent to payment for organs. An incentive is more an appreciation of the sufferings and trouble the donor has willingly taken on to help the recipient.

On the other hand, payment for organs occurs when these organs are actually sold, for a certain agreed price. An incentive is more like a way of saying thank you, expressing gratitude and trying to soothe the donor during his/her hard times, especially while healing after the transplantation. This procedure might not be necessary or practical in developed countries of the West, including Australia, Japan and Singapore, where the government provides subsidies and support for dialysis and transplant procedures; however, for most developing Asian countries such as the Philippines⁴⁸⁰ and Malaysia, where most of the patients must bear the cost of dialysis or transplantation from their own pockets, these incentives would really help ease their financial burden and suffering. Thus, if incentives were allowed, they would not only increase the numbers of those willing to donate organs, but at the same time would also provide compensation as appreciation for their willingness to do so. Both parties would definitely be happier and feel contented. However, allowing this might also raise arguments on how to clearly differentiate between payment for organs sold and incentives given for organs received. There may not be clear distinctions between the two, although the researcher believes that, in cases where organs are sold, there would definitely be elements of profit involved, as the price of the organs would be negotiated and bargained for before the actual transplantation procedure even takes place. In contrast to incentives, the amount would be as much as the organ receiver is willing to give. In other words, the amount is not fixed compulsorily before the transplantation procedure takes place but depends on the generosity of the recipient himself.

⁴⁸⁰ *Ibid*

This research is further supported by a study conducted with 434 university students in China to understand their knowledge of and attitude towards living organ donation. 48.0% preferred partial compensation for donation as opposed to a fully free, voluntary approach. Only a few were willing to donate under legal coercion or as part of the organ trade. This suggests that organ donation is not entirely motivated by altruism, and people do have an aversion to coerced participation⁴⁸¹. So, the above discussion indicates that providing incentives might be a practical solution to encourage more people to consider donating their organs to those in need. The incentive need not be equal to the value of the organ given as organs are indeed invaluable, but it should be at least sufficient to cover the medical expenses and sufferings of the donor himself and his family.

Another related issue is how to ensure that incentives are given for organs taken. This issue is more obvious in cases involving cadaver donors since the donor is no longer alive. Compared to living donor cases, the incentive could be given immediately after the transplantation procedures have been carried out, whatever the outcome of the transplant procedure. Alternatively, incentives could be paid to the deceased donor's family. Usually, the government would help the donating families financially in addition to recognition and benefits, such as funeral expenses and transportation of the body⁴⁸². Nevertheless, an even bigger challenge is to change the minds of the 88 respondents (18.3%) who strongly claimed that nothing could ever change their decision to refuse to become organ donors.

The findings of the study also show that Malaysians would be willing to allow the government to take their organs if they had no chance of survival, after being involved in a serious road accident. A percentage of 55.6% agreed with the notion, although the remaining 44.4% were against it. One can imagine how many potential organs could be retrieved by implementing the above suggestion given that 77.2% of the respondents possessed driving licenses and are on the road daily. However, it is interesting to discover

⁴⁸¹ Zhang, L, Li, Y, Zhou, J, et al. 'Knowledge and Willingness toward Living Organ Donation: A Survey of Three Universities in Changsha, Hunan Province, China' (2007) 39 *Transplantation Proceedings*, 1303-1309 p.1308.

⁴⁸² Shaheen, F.A.M. and Souqiyyyeh, M.Z, 'Ethical Issues in Organ Harvest and Distribution' (2003) 35 *Transplantation Proceedings*, 1217-1218

that a large majority of 88.0%, representing 424 respondents, wanted their families to be consulted first before any organ-harvesting took place at all. A detailed discussion on this suggestion is included in chapter six of the thesis. Nevertheless, this reflects the attitude of Malaysians, who regard family institutions as important elements in life; thus, they always return to them for reference and support. Nevertheless, the study also revealed that this does not in any way mean that families should be more authoritative than the individual him/herself. Regarding the issue of whether families should be allowed to override the decision to donate organs, more than half of the respondents (54.4 %) did not agree with this practice. Only 45.6% still preferred their families to be allowed to veto their decision. These results show that, despite the importance of referring the matter to their families, this does not extend to having families override their prior decision to donate organs. Indirectly, this shows that there is positive support and approval for possible amendment of the existing Human Tissues Act 1974, which still allows close family members to override existing decisions made by the deceased.

Finally, at the end of the study, the respondents were asked about their preferences were the existing opting-in system to be changed to the opting-out system. From the results of the study, it showed that there is an equal view on whether to accept this suggestion or not. 180 respondents rejected the suggestion, 172 respondents were prepared to accept the change and 130 were undecided. This result could be interpreted as a total split between those in favour and those against the idea of changing to opting out. The remaining 130 respondents, who did not specify their preference, could be interpreted as representing the group lacking information on the systems available. This shows that information on the matter must be disseminated clearly so that they too can decide and contribute to the debate, helping to produce a clearer result.

4.6 CONCLUSION

The results obtained from this study suggest that there is still a lot to be done to improve organ donation in Malaysia. These results are indicators representing the entire public perspective on the matter. As factors such as consent, family rejection, incentives and others are very much related to improving the overall situation, they cannot simply be put aside and will be addressed specifically in the subsequent chapters. Hopefully, the results of this study will also contribute in helping plan the next steps necessary to solve the organ shortage in Malaysia.

CHAPTER 5

CADAVERIC ORGAN DONATION AS THE BEST POSSIBLE SOLUTION

INTRODUCTION

The organ shortage problem remains unresolved, as the search for potential organs continues. Fortunately, people now realize that the supply of these much-needed human organs could obviously come from both living and cadaveric donors. However, cadaveric organ donation often remains underutilized due to continuing debates in the medical community, particularly on the concept of brain death, and insufficient awareness among the lay public⁴⁸³ about its potential to become a solution for organ shortage problems. Besides that, cultural and social factors, especially family relations and filial obligations, have also negatively influenced cadaveric donations. Therefore, this chapter will highlight the possibility of utilizing cadaveric organ donations as a solution to the organ shortage problem while looking into the advantages it offers compared to living donations. A discussion on the concept of brain death is included as misunderstandings about it have often affected people's willingness to allow cadaveric organ donations to take place. The chapter will also ask whether the authority to decide on organ donation should be passed to others, besides the individual him/herself, particularly when the deceased had left no clear wishes about it. Finally, a discussion justifying why the "opting out" system is not yet suitable for Malaysia is included.

5.1 CADAVERIC DONATIONS AS THE SUPPLY FOR THE NEEDED ORGANS

Cadaveric donations can be classified into two types: 'controlled' and 'uncontrolled' donations. 'Controlled' cadaver donations involve organs taken from patients with irreversible fatal brain injuries who are on life-supporting treatment which is later withdrawn in a controlled manner. This normally takes place in an intensive care or high

⁴⁸³ Shaheen F.A.M. and Souqiyyeh, M.Z. 'Improving Transplantation Programs and Patient Care', (2005) *37 Transplantation Proceedings*, 2909-2910, p.2910

dependency setting in the hospital and is also known as heart-beating donation⁴⁸⁴. Conversely, ‘uncontrolled’ cadaver donation or non-heart-beating donation involves the use of organs from patients who are already confirmed to be dead on arrival in emergency departments or those who have failed to respond to cardiopulmonary resuscitation within the hospital⁴⁸⁵. Nevertheless, in both categories, the organs are still generally suitable for transplantation purposes although different organs do have different durabilities.

Despite the use of live donation, by far the most fruitful source of organs is from people who have died⁴⁸⁶. If organs could be taken from more cadaveric donors, definitely many more lives could be saved, as potential cadaver donors are widely available. Every day, plenty of death cases are reported, caused by road traffic accidents. According to Lee Lam Thye, Chairman of the Public Awareness for Organ Donation Committee of Malaysia, were the necessary action to be taken, these essential cadaveric organs could potentially be donated and utilised as possible organ resources and contribute towards solving organ shortage problems⁴⁸⁷. This is the reason why effective and practical steps must be taken immediately to make use of these valuable resources which, to this day, are being frustratingly wasted. In Malaysia, cadaveric donations are recognised and there is much support for this alternative, as shown in the recent study conducted⁴⁸⁸. Results positively show that 45.0% of the respondents preferred donating organs after death and 41.5% are willing to donate organs both during their lifetime and after death. Only a small percentage of 13.5% opted to become living donors. These results optimistically demonstrate support for cadaveric organ donation rather than live donations. Indirectly, it can be perceived that, with the help of aggressive promotion and support to boost

⁴⁸⁴ Andy R Weale and Paul A Lear, ‘Organ Transplantation and the Human Tissue Act’, (2007) 83 *Postgrad Med J*, 141-142.

⁴⁸⁵ *Ibid.*

⁴⁸⁶ Sheila A.M. McLean and Laura Williamson, *Xenotransplantation Law And Ethics*, (Ashgate Publishing Limited, Aldershot, 2005), p.6

⁴⁸⁷ Jade Chan, *Organ Donation a Gift of Life*, 31 July 2009, The Star Online, <http://www.thestar.com.my>, viewed on 20 October 2010

⁴⁸⁸ Results obtained from an empirical study by the researcher relating to the organ shortage problems in Malaysia conducted from December 2007 until February 2008. The study took place in Klang Valleys specifically in Kuala Lumpur and the district of Hulu Langat. Detailed results of the study are further elaborated and discussed in chapter 4 of the thesis.

cadaveric donations, more potential organs could be generated from this source in the near future and perhaps one day could be incorporated as part of Malaysia's public policy in promoting organ donation activities.

5.2 ADVANTAGES OF RESORTING TO CADAVER DONATIONS

The use of cadaveric organs for organ donation purposes should be considered by society as a potential promise of its own future health⁴⁸⁹. This is because it allows potential organs to be shared while providing a chance of life for everybody in need of them⁴⁹⁰. Resorting to cadaveric donors offers no risk for the deceased donor⁴⁹¹, whereas living donors risk their own health through the act of donation⁴⁹². This explains why some people feel reluctant to become living donors, and why those who donate are normally motivated by prudential reasons such as shared interests, or by a sense of obligation grounded in emotional relations⁴⁹³. Apparently, a lot of living donations are between spouses, siblings, parents and children and sometimes between intimate friends⁴⁹⁴. However, related donors are not always available or may simply not exist. The intended recipient may have no close surviving relatives, or they may be too old, too young or too frail to undergo the organ donation surgery⁴⁹⁵. There are cases where they are simply not willing to make the sacrifice requested. So, in these particular cases, by resorting to cadaveric donations, all these troubles could be avoided, and the problem immediately solved. Moreover, people are more inclined to accept organs from unrelated living donors, as this practice can save the patient's life all the same⁴⁹⁶. Moreover, there is a view that, once the deceased has already died, logically his/her body will experience no

⁴⁸⁹ Felix Cantarovich, 'Organ Shortage, Are We Doing Our Best?', (2004) Vol.9, No.1, *Annals of Transplantation*, 43-45, p.44

⁴⁹⁰ *Ibid*

⁴⁹¹ Paul J. Ford and Toni Ann Nicoletti, 'My Organs, My Choice', (2005) *The American Journal of Bioethics*, July/August, Volume 5, Number 4, 30-31

⁴⁹² Raza, M. and Hedayat, K.M. 'Some Sociocultural Aspects of Cadaver Organ Donation: Recent Rulings from Iran', (2004) 36 *Transplantation Proceedings*, 2888-2890, p.2889.

⁴⁹³ Walter Glannon, 'Underestimating The Risk in Living Kidney Donation', (2008) 34 *J Med Ethics*, 127-128, p.127

⁴⁹⁴ *Ibid*

⁴⁹⁵ Martyn Evans, 'Organ Donations Should Not Be Restricted To Relatives', (1989) 15 *Journal of Medical Ethics*, 17-20, p. 17

⁴⁹⁶ *Ibid*

pain nor suffer any violation of integrity from the donation procedures⁴⁹⁷. So, there is no issue surrounding the vitality of the donor and the concern is focused solely on the authorisation to remove the organs⁴⁹⁸. Therefore, it is essential to consider more urgent concerns and save precious lives, rather than extending control over matters where the good of others should be the predominant concern⁴⁹⁹. So, while the persisting interests of the deceased and the wishes of the next of kin should be respected, the interests of living persons must also be protected to prevent them from continuous suffering, and their families need not be bereaved for want of donor organs⁵⁰⁰.

Consequently, when living donors are resorted to, it is not a complication-free procedure⁵⁰¹. Both the donor and recipient are exposed to common harm and risks following any medical procedure, such as pain and infections; however, the mortality rate associated with surgery on live donors is relatively low⁵⁰². Nevertheless, the risks associated with the donation of different types of organs by living donors actually differ according to the type of organ donated. For instance, the risks associated with living-donor liver lobe transplantation are greater than those associated with living donor kidney transplantation⁵⁰³.

Nevertheless, the general rule applicable is still the dead donor rule, which is a universal and central element of moral and legal frameworks relating to organ procurement, where patients must not be killed by the removal of organs⁵⁰⁴. So, patients must be declared dead before the removal of any vital organs for donation⁵⁰⁵. Although there are situations

⁴⁹⁷ Margareta A. Sanner, 'Promoting the Interdisciplinary Study of Death and Dying', (2006) *Mortality*, Vol.11, No.2, May, 133-150, p.140

⁴⁹⁸ Bagheri A, 'Individual Choice in the Definition of death', (2007) 33 *J.Med. Ethics*, 146-149, p.147

⁴⁹⁹ H E Emson, 'It Is Immoral To Require Consent For Cadaver Organ Donation', (2003) 29 *Journal Medical Ethics*, 125-127.

⁵⁰⁰ Harris J, 'Organ Procurement : Dead Interests, Living Needs', (2003) 29 *J Med Ethics*, 130-134 editorial

⁵⁰¹ Mahdanian A, 'Iranian Model of Living, Non-Related Kidney Donation : A Style To be Condemned Ethically', (2008) 34 *Medical Humanities*, 120

⁵⁰² Walter Glannon, 'Underestimating The Risk in Living Kidney Donation', (2008) 34 *J Med Ethics*, 127-128, p.127

⁵⁰³ *Ibid*

⁵⁰⁴ David Price, *Organs and Tissue Transplantation* (Aldershot, Ashgate Publishing Company, 2006) p.

xv.

⁵⁰⁵ Robert D.Truog and Franklin G. Miller, 'The Dead Donor Rule and Organ Transplantation', (2008) 359; 7 *N Engl J Med*, August 14, p.674-675

where a person may claim to have consented to such infliction, this is not an acceptable excuse or defence. It is also not enough for a competent adult to argue that he/she has the right to take such risks because, later, during the operation, the donor becomes a patient him/herself⁵⁰⁶. Therefore, one could only consent to donate a part of one's body if such a donation causes no appreciable harm; or, if there is at least slight harm inflicted, it must be greatly outweighed by the resultant benefits⁵⁰⁷. After all, we all have a duty to protect the individual donor from any harm and exploitation that might arise from his/her vulnerable position⁵⁰⁸. Donation of the bone marrow is a good example of a procedure well-known to be harmful, painful, and requiring hospitalisation and a general anaesthetic; but, at the same time, the advantages are extremely beneficial for the recipient. Due to this balance, and the fact that bone marrows are regenerative in nature⁵⁰⁹, this donation is regarded as both laudable and accepted as legal practice⁵¹⁰.

Undoubtedly, excellent outcomes are reported for organ recipients from living donations, particularly as this procedure constitutes an incremental source of kidneys⁵¹¹. Kidneys transplanted from living donors confer greater benefit than those from cadaveric donors because they provide superior graft and better patient survival⁵¹². Additionally they can prevent the need for, or at least reduce the duration of, dialysis, particularly for individuals with end-stage renal disease, while improving their quality of life tremendously⁵¹³. However, although the living donor benefits emotionally, there is no guarantee how long this feeling will last, as there is always a possibility that the transplant might later fail. For example, the survival of grafted organs from donors in kidney transplant recipients is not permanent, as recipients might need a second

⁵⁰⁶ Ross LF, Glannon W, Josephson MA, et al, 'Should All the Living Donors Be Treated Equally?', (2002) 74 *Transplantation*, 418-421

⁵⁰⁷ Sheila Mc Lean & John Kenyon Mason, *Legal & Ethical Aspects of Healthcare*, (London, Greenwich Medical Media Limited, 2003) p.188

⁵⁰⁸ Martyn Evans, 'Organ Donations Should Not Be Restricted To Relatives', (1989) 15 *Journal of Medical Ethics*, 17-20, p. 18

⁵⁰⁹ *Ibid*, p. 17

⁵¹⁰ Sheila Mc Lean & John Kenyon Mason, *Legal & Ethical Aspects of Healthcare*, (London, Greenwich Medical Media Limited, 2003) p.188

⁵¹¹ Rashad S.Barsoum, 'Trends in Unrelated-Donor Kidney Transplantation in the Developing World', (2008) 23 *Pediatr Nephrol*, 1925-1929, p.1925

⁵¹² Walter Glannon, 'Underestimating The Risk in Living Kidney Donation', (2008) 34 *J Med Ethics*, 127-128, p.127

⁵¹³ *Ibid*

transplant some 20 or 30 years later⁵¹⁴. This is not to mention the constant risk of earlier organ rejection and failure due to ischaemia⁵¹⁵ occurring during organ procurement and transplant⁵¹⁶. So, although there is a sustained emotional benefit achieved, this has to be weighed against the long-term physiological risk posed to the living donor in particular.

Generally, any organ donation must avoid harming or putting at undue risk those who are willing to become living donors⁵¹⁷. However, any removal of the kidney from a healthy living donor, for instance, might consequently cause the donor to develop diabetes and end-stage renal disease as well⁵¹⁸. If this risk materialises, the years of high-quality life of a person who was originally healthy are taken away when, actually, there is the alternative of resorting to a cadaveric donor instead. Consequently, although the recipient's quality of life may be better for a longer period with an organ from a living donor, the difference between the quality and quantity of life for the recipient of a kidney from a living or cadaveric donor is not as significant as the difference between health and disease for an individual who develops complications after making an organ donation⁵¹⁹. And although there might be some moral acceptability in physically harming a healthy, living, individual to allow this person to donate an organ to another, even in emotionally related cases, it would still be preferable for such healthy individuals to avoid taking such risks, as there are alternative sources, especially from cadavers⁵²⁰. This has been proved in the USA, where it was reported that 56 of 50,000 previous living kidney donors

⁵¹⁴ *Ibid*

⁵¹⁵ Ischaemia-Insufficient blood supply for the need of a part of the body, usually as a result of a disease of the blood vessels supplying that part. *Note*: also spelt ischemia. Dictionary of Optometry and Visual Science, 7th edition, 2009 Butterworth-Heinemann <http://medical-dictionary.thefreedictionary.com/ischaemia>, Viewed on 5 November 2009.

⁵¹⁶ Walter Glannon, 'Underestimating The Risk in Living Kidney Donation', (2008) 34 *J Med Ethics*, 127-128, p.128

⁵¹⁷ Paul J. Ford and Toni Ann Nicoletti, 'My Organs, My Choice', (2005) *The American Journal of Bioethics*, July/August, Volume 5, Number 4, 30-31

⁵¹⁸ Walter Glannon, 'Underestimating The Risk in Living Kidney Donation', (2008) 34 *J Med Ethics*, 127-128, p.128

⁵¹⁹ *Ibid*, p.127

⁵²⁰ Lainie Friedman, Walter Glannon, Michelle Josephson and Richard Thislethwaite J, 'All Living Donors Should Not Be Treated Equally', (2003) *Transplantation*, Vol.75, No.10, 1762-1763

had been listed for transplants themselves⁵²¹. Additionally, 104 Americans on the current transplant list had previously contributed as living organ donors⁵²².

While retrieving organs from cadavers is obviously better than resorting to living donors generally, one unavoidable challenge is to approach the deceased's family and confront their response regarding organ donation. This step provokes different reactions, either of a positive or negative type. Nonetheless, the medical staff have no choice, as any organs taken from cadavers for transplantation purposes must be removed quickly, soon after death occurs. Organs can easily deteriorate and become functionless once the body ceases breathing and stops receiving an oxygen supply. Therefore, to maximize the utility of these cadaver organs, there is a need to minimize the time between cessation of cardiac function and removal of the organs⁵²³. This explains the reason why the family members and relatives of the deceased, although still in shock after receiving news of the death and grieving over it, are nevertheless approached for consent and agreement for the removal of the deceased's organs. In most situations, the grieving family might feel offended and subsequently respond by denying consent for organ donation to take place. However, families must be encouraged to discuss organ donation, particularly to facilitate in respecting the deceased's wishes⁵²⁴.

In the absence of a known decision from the deceased, health professionals should be aware of their responsibility to discuss the issue with the family⁵²⁵. Therefore, to make this process easier, family members must comprehend the related concept of brainstem death⁵²⁶ to help them decide on the possibility of donating the deceased organs to others. Having said this, it is duly essential for family members to be approached at the right

⁵²¹ Brown RS Jr, Russo MW, Lai M, et al, 'A Survey of Liver Transplantation From Living Adult Donors in the United States', (2003), 348 *N Engl J Med*, 818-825

⁵²² Davis C, 'Living Kidney Donation: Controversies and Realities; Donor Risks' in Program and Abstracts of the American Transplant Congress, May 21-25, 2005, Seattle, Washington, Mount Laurel: American Transplant Congress, 2005.

⁵²³ Jerry Menikoff, 'The Importance of Being Dead: Non-Heart-Beating Organ Donation', (2002) *Issues in Law & Medicine*, Volume 18, Number 1, p.13

⁵²⁴ Irene Carey and Karen Forbes, 'The Experiences of Donor Families in the Hospice', (2003) 17 *Palliative Medicine*, 241-247, p.241

⁵²⁵ *Ibid*

⁵²⁶ Arabella L Simpkin, Laura C Robertson, Vicki S Barber and J Duncan Young, 'Modifiable Factors Influencing Relatives' Decision To Offer Organ Donation: Systematic Review, (2009) *BMJ*, 338:b3911

time and in the right way, in order to ensure many more organ donation procedures are consented to. According to Simpkin and colleagues, just by modifying the process of requesting consent, the organ donation rate could possibly increase⁵²⁷. They suggested that the request for organ donation be made separately from the notification of death, including making the request in a private setting⁵²⁸. Additionally, the best person to discuss and bring forward such organ donation issues to the family is the organ procurement coordinator officer⁵²⁹, and a second approach should be considered if the first attempt was not successful, as there is a possibility that people might change their minds after some time⁵³⁰. Other challenges faced in realising cadaver donations include poor organisation, apathy, bureaucracy, inadequate laws, uninterested politicians, doctors being busy with other matters, and uncomfortable feelings about the concept of brain death⁵³¹. And even though organ donation might seem to benefit the organ recipients more than the donors, we should also take note of the major emotional and mental strains they have experienced while waiting for any potential organs to become available, including having to prepare for the possibility that the organ donation procedure might even fail.

5.3 THE BRAIN DEATH CONCEPT

Traditionally, before the development of modern critical care, the diagnosis of death was relatively straightforward as patients were considered dead when they were cold, blue and stiff⁵³². These features actually indicated cardiac death; however, later, this became outdated as life could be prolonged through artificial ventilation⁵³³. The new definition of death was then referred to as the occurrence of irreversible degeneration of the brainstem. This concept of brain death first emerged in France in 1959, when a group of

⁵²⁷ *Ibid*

⁵²⁸ *Ibid*

⁵²⁹ Siminoff, LA, Gordon N, Hewlett J, Arnold RM, 'Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation', (2001) 286 *JAMA*, 71-77.

⁵³⁰ *Ibid*

⁵³¹ Daar, A.S 'The Evolution of Organ Transplantation in the Middle East', (1999), 31 *Transplantation Proceedings*, 1070-1071, p.1070.

⁵³² Robert D. Truog and Franklin G. Miller., 'The Dead Donor Rule and Organ Transplantation' (2008) *N Engl J Med*, 359, 7 August, 14

⁵³³ Jean McHale and Marie Fox. *Health Care Law Text and Material*, second edition, (Thomson Sweet & Maxwell, London, 2007) p.1089

neurosurgeons described a condition of persistent apnoeic coma, absent brainstem and tendon reflexes and an electrically silent brain as the death of the central nervous system⁵³⁴. At this point, the patients looked like cadavers although a regular pulse continued as long as the ventilation machine was still connected. They advocated that should this condition persist for 18 to 24 hours, it would warrant disconnection from the ventilator⁵³⁵.

Later in the same year, two Parisian neurologists, Mollaret and Goulon, managed to further classify a more comprehensive set of criteria of massive irreversible coma which included conditions such as irreversible loss of the capacity to breathe and respond to external stimuli, inability to cope with one's internal milieu including being poikilothermic, having diabetes insipidus and being unable to sustain one's own blood pressure⁵³⁶. This term 'irreversible coma' is actually equivalent to the term 'brain death' used nowadays. Later, in 1968, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, chaired by Henry Beecher, published the Harvard Criteria for Brain Death which included the following:

- 1) absence of cerebral responsiveness;
- 2) absence of induced or spontaneous movement;
- 3) absence of spontaneous respiration;
- 4) absence of brainstem and deep tendon reflexes⁵³⁷.

This committee reported that there were two main reasons for the need to provide specific definitions of brain death. The first was related to improvements in resuscitative and supportive measures, causing medical staff to increase their efforts on behalf of those severely injured especially when the heart continues to beat but the brain is irreversibly damaged; the second triggering factor was the need to avoid any controversies in obtaining organs for transplantation⁵³⁸.

⁵³⁴ Lamb, D, *Organ Transplants and Ethics*, (London, Routledge, 1990)

⁵³⁵ *Ibid*

⁵³⁶ *Ibid*

⁵³⁷ *Ibid*

⁵³⁸ Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, "A Definition of Irreversible Coma", (1968) 205 *JAMA*, 337-340.

To this day, the concept of brain death has served us well and has been the ethical and legal justification for thousands of lifesaving donations and transplantations⁵³⁹. The medical criteria for identifying brainstem death⁵⁴⁰ are indeed well-established and there are certain guidelines for the certification of death by brainstem testing. The commonest causes of brainstem death are brain injury and cerebral haemorrhage, usually occurring unexpectedly in young, healthy individuals with no premorbid symptoms⁵⁴¹, and which are mostly found in road traffic accident victims⁵⁴². There is often no external sign of injury and, although the brainstem is dead, the patient is warm and pink due to inotropes and warming devices, and the chest rises and falls due to artificial ventilation⁵⁴³. In some places, there are even monitors available showing images of the heart beating⁵⁴⁴. Therefore, to a casual observer, these patients seem very much alive and look just like patients who are receiving long-term artificial ventilation and are asleep⁵⁴⁵.

According to the Intensive Care Society document, brainstem death is diagnosed in three stages. First, it must be established that the patient had suffered an event of known cause resulting in irreversible brain damage with apnoeic coma, i.e. the patient is deeply unconscious and mechanically ventilated with no spontaneous respiratory movement. Second, there are no reversible causes of coma; and, finally, a set of bedside clinical tests of brainstem function are also taken to further confirm the diagnosis of brainstem

⁵³⁹ Robert D. Truog and Franklin G. Miller, 'The Dead Donor Rule and Organ Transplantation', (2008) 359; *7 N Engl J Med*, August 14, p.674-675, p.674

⁵⁴⁰ 'Brain stem death'-Death diagnosed and certified following neurological tests of brain stem function. The diagnosis of death can be made whilst the body of the person is attached to an artificial ventilator, and whilst the heart is still beating; 'brain stem', on the other hand, is defined as the critical part of the brain that is responsible for consciousness, breathing and other functions that are essential for life, cited from 'Organs for Transplants, A Report from the Organ Donation Taskforce, January 2008, p.56

⁵⁴¹ Ormrod, J.A, Ryder, T. Chadwick R.J, and Bonner, S.M. Experiences of Families When A Relative Is Diagnosed Brain Stem Dead: Understanding Of Death, Observation of Brain Stem Death Testing and Attitudes to Organ Donation', (2005) 60 *Anaesthesia*, 1002-1008, p 1002

⁵⁴² Tymstra, TJ, Heyink, JW, Pruijm, J and Sloof, MJH, 'Experience of Bereaved Relatives Who Granted or Refused Permission For Organ Donation', (1992) *Family Practice*, Vol.9, No.2, 141-144, p.142.

⁵⁴³ Ormrod, J.A, Ryder, T. Chadwick R.J, and Bonner, S.M. Experiences of Families When A Relative Is Diagnosed Brain Stem Dead: Understanding Of Death, Observation of Brain Stem Death Testing and Attitudes to Organ Donation', (2005) 60 *Anaesthesia*, 1002-1008, p 1002

⁵⁴⁴ Tymstra, TJ, Heyink, JW, Pruijm, J and Sloof, MJH, 'Experience of Bereaved Relatives Who Granted or Refused Permission For Organ Donation', (1992) *Family Practice*, Vol.9, No.2, 141-144, p.141.

⁵⁴⁵ Robert D. Truog and Franklin G. Miller, 'The Dead Donor Rule and Organ Transplantation', (2008) 359; *7 N Engl J Med*, August 14, p.674-675, p. 674.

death⁵⁴⁶. These criteria for the diagnosis of brainstem death have also been adopted by the courts in England and Northern Ireland for the certification of death⁵⁴⁷. They have also been recognised worldwide⁵⁴⁸ and are implemented widely in organ donation activities and family directives⁵⁴⁹. However, there are still disagreements over this way of defining and confirming death which replaces the traditional process of establishing that there is no heartbeat and that breathing has stopped⁵⁵⁰.

Some extreme groups argue that the definition of death should even be extended to encompass those persons in a state of cognitive death or upper brain death which would include persons in a persistent vegetative state being recognised as “dead” too⁵⁵¹. The guidelines for the definition of death provided by the Department of Health, London, in 1998, laid down that death occurs when there is irreversible loss of the capacity to breathe and agreed that brainstem death is the accepted criterion to ascertain that death has actually occurred⁵⁵². The practice suggested is to alternatively have an isoelectric EEG, except in hypothermia and drug intoxication cases; this is deemed to be of great confirmatory value⁵⁵³. The same test is then repeated over a period of 24 hours to document the persistence of the condition⁵⁵⁴.

So, practically, a person in the state of brain death will suffer irreversible cessation of function of the whole brain - both the “higher” brain responsible for thinking and feeling,

⁵⁴⁶ House of Lords European Union Committee 17th. Report of Session 2007-08 *Increasing the supply of donor organs within the European Union*, volume 1, (London, The Stationary Office Limited, 2008), chapter 3, p. 18, para 67 and footnote 19

⁵⁴⁷ *Ibid*, para 67

⁵⁴⁸ Wijdicks EFM, ‘Brain Death Worldwide: Accepted Fact But No Global Consensus in Diagnostic Criteria’, (2002), 58 *Neurology*, 20-25.

⁵⁴⁹ David J Powner, ‘Certification of Brain Death: Take Care’, (2009), Vol 373, May 9, *The Lancet*, www.thelancet.com, p.1587-1588, p.1587.

⁵⁵⁰ *Ibid*, para 68

⁵⁵¹ Jean McHale and Marie Fox. *Health Care Law Text and Material*. (second edition, London, Thomson Sweet & Maxwell, 2007) p.1089

⁵⁵² A code of practice for the diagnosis of Brain Stem Death : including guidelines for the identification and definition of death and management of potential organ and tissue donors (London: Department of Health, 1998 quoted from Jonathan Montgomery, *Health Care Law*, (United States, Oxford University Press, 2003) p.453

⁵⁵³ Lamb,D, *Organ Transplants and Ethics*, (London: Routledge, 1990)

⁵⁵⁴ *Ibid*

and the “lower” brain responsible for maintaining the whole body’s functions such as breathing and maintaining a constant temperature⁵⁵⁵. Such a person will appear to be still breathing although that is actually because of the ventilator to which he or she is attached. And, because of this, oxygenated blood is still circulating through the person’s body keeping the organs healthy for some period of time even after the person has already been declared dead. These organs are those which are suitable and useful for transplantation purposes⁵⁵⁶.

According to the brain-dead theory mentioned above, numerous patients have been diagnosed as brain-dead, although some critics still feel that these brain death criteria were developed merely to allow vital organ donation and do not have a firm scientific or philosophical basis⁵⁵⁷. Previously, in the UK, even though the Human Tissues Act 1961 did not provide for an exact definition of death, it still required the doctor removing the parts of the body to be fully satisfied that, after personally examining the body, life had been extinguished before any organ donation procedures could take place⁵⁵⁸. This literally means that the law leaves it up to the medical practitioners to decide what death means for these purposes, since it is a complex concept and there is no certainty as to what tests should be applied.

Later, in 2008, an updated code of practice for the diagnosis of death was released; this provided clear scientific criteria for confirming brainstem death and death following cardiac arrests. The Code specifies that, for a declaration of death following irreversible cessation of brainstem functions, three things should be noted. First, the patient must no longer be able to breathe unaided without any respiratory support along with other life-sustaining biological interventions. Second, there is cessation of all neurological activity in the brain, causing an absence of consciousness normally associated with human life; and, lastly, although the body might continue to show signs of biological activity after the

⁵⁵⁵ Jerry Menikoff, ‘ The Importance of Being Dead: Non-Heart-Beating Organ Donation’, (2002) *Issues in Law & Medicine*, Volume 18, Number 1, p.4

⁵⁵⁶ *Ibid.*

⁵⁵⁷ Potts M and Evans D W, ‘Does It Matter That Organ Donors Are Not Dead? Ethical And Policy Implications’, (2005) 31 *J. Med. Ethics*, 406-409, p.408

⁵⁵⁸ S.1(4), (4A)

diagnosis of brainstem death, the patient actually can no longer benefit from any supportive treatment, and legal certification of death is appropriate⁵⁵⁹.

In the case of *Re A*⁵⁶⁰ the court had affirmed the application of the brainstem death test when it was asked to decide whether a child on life support was actually considered dead. 'A' was a young child, just under two years of age. He was taken to hospital where he was found to have no heartbeat and was suffering from non-accidental injuries, including having blood on the brain. He was put on a ventilator but there were no signs of recovery at all. The court then held that, once the accepted test establishes brainstem death, the child is actually already dead for legal purposes and, therefore, it was considered lawful to turn off the life support machine. In Japan, uniquely, individuals are allowed to choose the definition of death based on their own view⁵⁶¹. So, the individual may choose either cessation of cardio-respiratory function or loss of entire brain function for their death pronouncement. However, the choice is only available for cases where the organs are suitable for transplantation, with the agreement of the family⁵⁶². So, the family has the power to veto the individual's wish to donate, although they cannot be authorised to act as surrogate decision-makers and decide on behalf of the individual, who is in a brain-dead state and whose organ donor card cannot be found⁵⁶³.

In spite of all these disputes over the exact definition of brain death, doctors are strictly advised to adhere to testing that does not risk further injury to the patient and that provides an infallible conclusion⁵⁶⁴. The official time of death is actually the same time the diagnosis of brain death is pronounced⁵⁶⁵. As brainstem death can be a difficult

⁵⁵⁹ A Code of practice for the Diagnosis and Certification of Death, 2008, Academy of Medical Royal Colleges, p.11, <http://www.aomrc.org.uk/publications/reports-guidance>, viewed on 22 May 2011

⁵⁶⁰ [1992] 3 Med.LR 303

⁵⁶¹ Bagheri A, 'Individual Choice in the Definition of death', (2007) 33 *J.Med. Ethics*, 146-149, p.147

⁵⁶² *Ibid*

⁵⁶³ *Ibid*

⁵⁶⁴ David J Powner, 'Certification of Brain Death: Take Care', (2009), Vol. 373, May 9, *The Lancet*, www.thelancet.com, p.1587-1588, p.1587.

⁵⁶⁵ Tymstra, TJ, Heyink, JW, Pruijm, J and Sloof, MJH, 'Experience of Bereaved Relatives Who Granted or Refused Permission For Organ Donation', (1992) *Family Practice*, Vol.9, No.2, 141-144, p.144.

concept for families to understand⁵⁶⁶, it is important that it is clearly explained to them that, because brain death has occurred, the patient has actually died. If the idea of organ donation is to be subsequently suggested, it is preferable that the organ procurement team initiate it in order to ensure accuracy, sensitivity⁵⁶⁷ and full clarity on the deceased's condition⁵⁶⁸. Besides giving families time, understanding and explanations to help them understand the diagnosis, there are also suggestions that appropriate diagrams, leaflets and the patient's CT scan be used to ensure better understanding and perhaps, if necessary, to allow them to observe the brainstem death tests being carried out on the patient⁵⁶⁹. All this effort is essential, not just because it will reduce distress to the family, but because it will automatically facilitate more people to proceed with organ donations, as they will be aware of the fact that recovery is impossible for that particular patient⁵⁷⁰. A study by Tavakoli et al. also discovered that organ donation does not have a significant impact on the course of grief and depression among relatives of brain death cases; in fact, it positively alleviates their grief⁵⁷¹. So, once the families comprehend that brain death has occurred, and are able to consent to organ donation sooner, we might hopefully maximise the number and quality of organs donated.

5.4 WHO HAS RIGHTS OVER THE CADAVER?

There are various views regarding the property rights over the cadaver. It remains debatable whether the corpse can be considered as property in a legal sense or whether it can be considered as belonging to anyone after death. Some believe that there is property value in it, while others contend that this concept is inaccurate and morally wrong⁵⁷². The Common Law of England does not generally recognise property rights in corpses;

⁵⁶⁶ Ormrod, J.A, Ryder, T. Chadwick R.J, and Bonner, S.M. Experiences of Families When A Relative Is Diagnosed Brain Stem Dead: Understanding Of Death, Observation of Brain Stem Death Testing and Attitudes to Organ Donation', (2005) 60 *Anaesthesia*, 1002-100, p 1002.

⁵⁶⁷ Sheelagh McGuinness and Margaret Brazier, 'Respecting the Living Means Respecting the Dead Too', (2008) 28 *Oxford Journal of Legal Studies*, 297

⁵⁶⁸ Teresa J Shafer, 'Improving Relatives' Consent to Organ Donation', (2009) *BMJ*, 21 April, 338:b701.

⁵⁶⁹ Ormrod, J.A, Ryder, T. Chadwick R.J, and Bonner, S.M. Experiences of Families When A Relative Is Diagnosed Brain Stem Dead: Understanding Of Death, Observation of Brain Stem Death Testing and Attitudes to Organ Donation', (2005) 60 *Anaesthesia*, 1002-100, pp. 1002-1003.

⁵⁷⁰ *Ibid*, p 1002

⁵⁷¹ Tavakoli, S.A.H, Shabanzadeh, A.P, Arjmand, B et al, (2008) 40 *Transplantation Proceedings*, 3299-3302, p.3301

⁵⁷² Emson, H.E, 'It Is Immoral To Require Consent For Cadaver Organ Donation', (2003) 29 *Journal Medical Ethics*, 125-127

nonetheless, certain persons, such as executors, administrators and the next of kin do possess rights to handle the corpse for burial purposes⁵⁷³. Based on this ‘no property’ rule, the English Common Law also maintains that a dead body and any biological materials separated from it cannot be the subject of property rights unless its characteristics have changed⁵⁷⁴. Therefore nobody including the next of kin or any third party can claim proprietary rights over the corpse. It is also a general principle that a person does not own his or her body or its individual parts, which again supports the notion that there are no property rights in one’s body⁵⁷⁵. It is argued that, because human dignity is closely linked to humans’ embodiment, any act of treating the body and its parts as commodities would be equivalent to stripping the human body of its proper dignity⁵⁷⁶. For some religions, such as Islam for instance, the human body is believed to be the property of the Creator⁵⁷⁷, to which it will eventually be returned after death. So, as a person does not own his/her body, the individual is therefore not allowed to dispose of his/her own body by damaging it through amputation or extreme punishments. This is why Islam forbids mutilation and suicide⁵⁷⁸, although organ donation, in contrast, is permissible as an act of charity, benevolence and altruism, since it functions to save the lives of others⁵⁷⁹.

There is another interesting issue that subsequently arises: who has the authority to decide what will happen to the cadaver and its organs upon death? While still alive, undoubtedly each individual has authority over his or her body which includes having the right to determine what is done to it. Section 3(2) of the Human Tissue Act 2004 in the UK clearly states that, for a living person, the “appropriate consent” required would be

⁵⁷³ Remigius N.Nwabueze. *Biotechnology and the Challenge of Property; Property Rights in Dead Bodies, Body Parts, and Genetic Information*. (Aldershot, Ashgate Publishing Limited, 2007) p.98

⁵⁷⁴ Rohan Hardcastle, *Law and the Human Body; Property Rights, Ownership and Control*. (Oxford, Hart Publishing, 2007) p.28.

⁵⁷⁵ Sheila Mc Lean & John Kenyon Mason. *Legal & Ethical Aspects of Healthcare*. (London, Greenwich Medical Media Limited, 2003) p.179.

⁵⁷⁶ Leon R. Kass, “Thinking about the Body”, *The Hastings Center Report* 15, February 1985: pp 20-30 quoted in Bernard Teo., ‘Is The Adoption of More Efficient Strategies of Organ Procurement The Answer to Persistent Organ Shortage in Transplantation?’ (1992) *Bioethics* Volume 6 Number 2, 113-129, p. 125

⁵⁷⁷ El-Shahat, Y.I.M, ‘Islamic Viewpoint of Organ Donation’, (1999) 31 *Transplantation Proceedings*, 3271-3274, p. 3273

⁵⁷⁸ Al-Quran, Surah Al-Nisa’: 29, The translation of the verse is “...nor kill (or destroy) yourselves”

⁵⁷⁹ El-Shahat, Y.I.M, ‘Islamic Viewpoint of Organ Donation’, (1999) 31 *Transplantation Proceedings*, 3271-3274, p. 3273.

his/her own consent. But what happens if a person dies without leaving any express wishes on what should be done with the body? Is it acceptable to allow anybody else to have that authority to decide on behalf of the deceased, particularly on what should be done to the deceased's organs before burial or cremation procedures take place? It is undeniably crucial to be clear about whose wishes could possibly determine the procurement of cadaveric organs, as this will have a significant impact on the procurement rate; this could be even more important than expanding the legal scope of living wills which cover individuals' organ donation preferences⁵⁸⁰. Is it proper to allow the next of kin or perhaps the state to proceed with organ donation even if there is no evidence that the deceased had ever registered as a potential organ donor?

The guiding principles issued by the World Health Organisation (WHO) in 1991⁵⁸¹ state that organs may be removed from the body of a dead person if:

- a) any consents required by law are obtained; and
- b) there is no reason to believe that, in the absence of any formal consent given during life, the dead person would have objected to such removal.

If the above conditions are satisfied, it would obviously mean that, as long as consent is obtained legally, which does not necessarily need to be from the deceased him/herself during his/her lifetime, and as long as there is no sign or indication of such an objection from the deceased during his/her lifetime to his/her organs being removed and used, it would be possible for the deceased's organs to be transferred and donated to others.

Most countries legally permit removal of organs from the cadaver of a person who made known his/her wish to donate while alive⁵⁸². However, the fact that not many people make the effort to do so might be the reason why some countries legally allow consent to be sought from relatives as an alternative. Moreover, considering the fact that most potential donors will have spent some time in the hospital's Intensive Care Unit before

⁵⁸⁰ Wendler, Dave and Dickert, Neal, 'The Consent Process For Cadaveric Organ Procurement: How Does It Work? How Can It Be Improved?' (2001) *JAMA*, Vol 285(3), 17 January, 329-333, p. 230.

⁵⁸¹ WHO, Geneva. 1991. Human Organ Transplantation: A Report on Developments under Auspices of the WHO (1987-1991).p.7.

⁵⁸² Kennedy, I, et al, 'The Case for 'Presumed Consent'' in Organ Donation' (1998) *The Lancet*. Vol 351, May 30, 1650

death is pronounced, their relatives would seem to be the most suitable persons to be approached in seeking consent to remove the deceased's organs for donation. The fact that they are the ones present when the life support machine is removed makes them accessible and approachable for consent too⁵⁸³.

Previously in the UK, under the Human Tissue Act 1961, removal of organs for transplant could only be authorized if, firstly, the deceased person had clearly requested that his/her organs be used for transplant, for example, by carrying an organ donor card, or having registered with the organ donation registry. Secondly, in cases where the deceased had not clearly made any such request for his/her organs to be taken, the person lawfully in possession of the body had the authority to allow organ removal, after having made as reasonable an enquiry as was practicable and being satisfied that there was no reason to believe that the deceased had expressed any objections towards transplantation or that there were any objections from the surviving spouse or relative. Now, under the new Human Tissue Act 2004, the issue of consent is still given priority as, from the very start, section 1 clearly states that no organ can be taken without 'appropriate consent'. However, by virtue of this new Act, appropriate consent for adult donors can now be obtained through three different channels instead of only two previously. First, consent should be sought primarily from the deceased him/herself during his/her lifetime⁵⁸⁴ which could obviously be manifested by the carrying of a donor card or being registered on the organ donor register. Secondly, consent could be sought from a person or persons appointed by the deceased under section 4 to deal with his/her affairs post mortem⁵⁸⁵. Section 4 enables an individual to give a proxy decision-making power to another person to decide on their behalf and to further use their material after death. Section 4(1) states that an adult may appoint one or more persons to represent him/her after his/her death,

⁵⁸³ *Ibid.*

⁵⁸⁴ Section 3(6) (a)

"Where the person concerned has died and the activity is not one to which subsection (4) applies, "appropriate consent" means-
(a) if a decision of his to consent to the activity, or a decision of his not to consent to it, was in force immediately before he died, his consent;"

⁵⁸⁵ Section 3 (6) (b) (ii)

"he has appointed a person or persons under section 4 to deal after his death with the issue of consent in relation to the activity, consent given under the appointment;"

including in transplantation matters as listed in section 1. This appointment may be made general or limited to certain activities as specified in the appointment⁵⁸⁶ and the appointment can be made either orally or in writing⁵⁸⁷. If an oral appointment is made, it will only be treated as valid if it was made in the presence of at least two witnesses who are present at the same time⁵⁸⁸. Appointments made in written form, will be deemed valid if they have the signature of the person making it in the presence of at least one witness who attests to the signature⁵⁸⁹. However, in cases where two or more persons are appointed, they shall be regarded as appointed to act jointly and severally unless the appointment provides that they are appointed to act jointly⁵⁹⁰. And, lastly, if neither of the two groups above is available, the consent of a person who stood in a qualifying relationship with the deceased immediately before he/she died would be sufficient⁵⁹¹. So, in cases where the deceased person had not given their consent and had not nominated someone to give proxy consent, or under sections 3(7) and 3(8) where their nominee is unable to consent, or ‘it is not reasonably practicable to communicate with their nominee within the time available’, consent can be alternatively sought from someone in a qualifying relationship.

Qualifying relationships are defined in section 27(4) and are ranked accordingly. The full hierarchy is as follows:

⁵⁸⁶ Section 4(2) Human Tissue Act 2004

“An appointment under this section may be general or limited to consent in relation to such one or more activities as may be specified in the appointment”

⁵⁸⁷ Section 4(3) Human Tissue Act 2004

“An appointment under this section may be made orally or in writing”

⁵⁸⁸ Section 4(4) Human Tissue Act 2004

“An oral appointment under this section is only valid if made in the presence of at least two witnesses present at the same time”

⁵⁸⁹ Section 4(5) (a) Human Tissue Act 2004

“A written appointment under this section is only valid if-

(a) it is signed by the person making it in the presence of at least one witness who attests the signature,”

⁵⁹⁰ Section 4(6) Human Tissue Act 2004

“Where a person appoints two or more persons under this section in relation to the same activity, they shall be regarded as appointed to act jointly and severally unless the appointment provides that they are appointed to act jointly.”

⁵⁹¹ Section 3(6) (c) Human Tissue Act 2004

“if neither paragraph (a) nor paragraph (b) applies, the consent of a person who stood in a qualifying relationship to him immediately before he died.”

- a) spouse or partner (including civil or same-sex partner);⁵⁹²
- b) parent or child (in this context a ‘child’ can be any age);
- c) brother or sister;
- d) grandparent or grandchild;
- e) niece or nephew;
- f) stepfather or stepmother;
- g) half-brother or half-sister;
- h) friend of long standing.

Consent should be obtained from the person ranked highest⁵⁹³. For relationships that are listed together, for instance ‘brother and sister’, both are accorded equal status in ranking. Hence, it is sufficient to obtain consent from just one of them⁵⁹⁴. The same rule applies if there are two or more persons who are ranked of equal status in relation to the deceased - similarly, it is sufficient to obtain consent from any of them. Therefore, if the deceased had several children, the consent of only one child is required⁵⁹⁵.

In circumstances where the highest-ranked person in the qualifying relationship does not wish to deal with the issue of consent, or is not able to do so due to lack of capacity, or is not contactable, the principles applied to the ranking of qualifying relationships can be waived and the next person in the ranking should be approached⁵⁹⁶ because organs must be retrieved as quickly as possible after death occurs. One unique provision of the 2004 Act is to extend the opportunity for the decision to be made by a preferred decision-maker, such as a close friend, rather than being limited solely to family members who might have become alienated from the deceased individual. Although, at a glance, this arrangement seems very systematic and organised, David Price had doubts over the correctness of the arrangement of ranks laid down in the hierarchy. He added that,

⁵⁹² Section 54(9) states for these purposes a person is another person’s partner if the two of them (whether of different sexes or the same sex) live as partners in an enduring family relationship.

“The following are qualifying relationships for the purpose of this Act, spouse, partner, parent, child, brother, sister, grandparent, grandchild, child of a brother or sister, stepfather, stepmother, half-brother, half-sister and friend of long standing.”

⁵⁹³ Paragraph 54 Human Tissue Authority Code of Practice-Consent. Code 1 July 2006

⁵⁹⁴ *Ibid* Paragraph 55,

⁵⁹⁵ *Ibid*, Paragraph 56

⁵⁹⁶ *Ibid*, Paragraph 57

although it is understood and justified that requiring the consent of all or a majority would be impossible and unworkable, by virtue of this Act, once the consent of one qualifying relative has been given, no-one of a lesser 'rank' nor anyone of the same rank can veto that consent⁵⁹⁷. This might result in some practical difficulties and there might be a need for a system to record a person's objections to the taking and using of the organs after death, because one relative who objects on the basis of personal knowledge about the individual's reservations might be 'overruled' by another consenting relative of the same or a higher class⁵⁹⁸. It is also argued that giving relatives and close friends any say over what should happen to a person's body after his death is actually inconsistent with the now-dominant principle of patient autonomy⁵⁹⁹.

It is questionable that a family member who has absolutely no say over a person's medical treatment during his/her life should be able, in practice, to make decisions about whether or not to donate his/her (the deceased's) organs. However, if consideration is given more towards ensuring the emotional stability of the surviving family members, it might be possible to argue that, in organ donation matters, it is indeed the families that make the greatest sacrifice when organs are taken from the dead body, not the deceased him/herself⁶⁰⁰. "They must usually come to terms with the fact that someone dear to them has been transformed, in the space of a few hours, and often through a violent encounter, from a healthy individual into an irrevocable damaged entity, suspended between life and death"⁶⁰¹. Comparatively, the position in Malaysia is totally different. The Human Tissues Act 1974 under section 2(1) provides as follows:

"If any person, either in writing at any time or orally in the presence of two or more witnesses during his last illness, has expressed a request that his body or any specified part of his body be used after his death for therapeutic purposes, or for purposes of medical education or research, the person lawfully in possession of his body after his

⁵⁹⁷ The Human Tissue Act 2004, (2005) 68 *Modern Law Review*, 798-821

⁵⁹⁸ David Price, 'The Human Tissue Act 2004', (2005) 68 *Modern Law Review* 798-821

⁵⁹⁹ Emily Jackson. *Medical Law Text, Cases, and Materials*, (Oxford, Oxford University Press, 2006) p.711.

⁶⁰⁰ Margaret Lock, *Twice Dead: Organ Transplants and Reinvention of Death* (University of California Press Berkeley, 2002) p.373.

⁶⁰¹ *Ibid*

death may, unless he has reason to believe that the request was subsequently withdrawn, authorize the removal from the body of any part or, as the case may be, the specified part, for use in accordance with the request.”

The above section clearly mentions how consent can be given by the individual him/herself in deciding whether or not to become an organ donor. This consent can be expressed at any time during his/her lifetime in writing or orally. If the consent is made orally, the presence of two or more witnesses during his/her last illness is necessary. It is also up to that particular individual alone to decide whether to donate their whole body or only specific parts of the body and for either therapeutic, medical education or research purposes.

Once the death of the individual occurs, the person lawfully in possession of the body may authorize the removal from the body of any part or the specified part as requested unless there is any reason to believe that the individual’s consent had been subsequently withdrawn or any objections for such removal had been expressed by the deceased himself during his/her lifetime or by his/her surviving spouse or any surviving next of kin. Therefore, the person lawfully possessing the deceased body is only consulted as a proxy for the deceased donor, and is not making an independent judgement⁶⁰². The following subsection lists the powers provided to the person ‘lawfully in possession’ of the deceased body. Section 2(2) of the Human Tissues Act 1974 states:

“Without prejudice to the foregoing subsection, the person lawfully in possession of the body of a deceased person may authorize the removal of any part of the said body for use for the purpose aforesaid if, having made such reasonable enquiry as may be practicable he has no reason to believe-

a) that the deceased had expressed an objection to his body being so dealt with after his death; or

b) that the surviving spouse or any surviving next- of- kin of the deceased objects to the body being so dealt with.

⁶⁰² George Galea and D Pegg, ‘The Ethics of Donation: Changes Are Necessary and Soon’, (2003), *The Lancet*, Vol 362, September 20, www.thelancet.com.

3) No authorisation shall be given under this section in respect of any body by a person entrusted with the body for the purpose only of its internment or cremation.”

The above subsection authorizes the ‘person lawfully in possession’ of the deceased body to remove any part or parts of the deceased body according to the deceased’s prior express request, provided that there are no express retractions or objections made by the deceased him/herself afterwards or that there are no objections from any surviving spouse or next of kin of the deceased either. Also by virtue of this subsection, dominant power is allocated to surviving relatives to oppose and overrule any existing wishes made by the deceased relating to his/her body. However, if the ‘person lawfully in possession’ is entrusted only with dealing with matters related to the internment and cremation of the deceased body, he/she does not have power to authorise or initiate any removal of the body parts through his/her own wishes.

Although the 1974 Act seems to allow only the particular individual himself to decide on organ donation matters, the National Organ, Tissue and Cell Transplantation Policy released in June 2007 has clearly extended the decision-making power to include the next of kin of the deceased. In paragraph 6.3.7 it states:

“Consent for donation can be obtained either from the deceased’s expressed wish made through the organ and/or tissue donor pledge card and/or from the next of kin.”

This development clearly shows the expansion of power provided in our efforts to obtain as many organs as possible to solve the organ shortage problem. Perhaps, with the expansion of the authority to decide, so as to include close relatives deciding on behalf of the deceased, more organ donations could take place. However, the changes have not gone to the extent of allowing close friends to decide as well, as practised in the UK. Nonetheless, in all situations, the element of consent has never been set aside and has always been a required priority in all cases as portrayed in the 1974 Act and the recent 2007 policy.

Although some people might prefer the disposal of their body and decision on removal of its body parts to be left to their surviving close relatives, or even extended to their close friends, the researcher, to the contrary, would prefer the individual to have full authority

to decide what should happen to his/her cadaver body and its body parts. So, if the deceased had not registered as an organ donor and had failed to tell anyone of their wish to do so, this should give rise to the conclusion that the deceased person was not in favour of organ donation⁶⁰³. The researcher finds it quite disturbing to accept the fact that surviving, close relatives are legally allowed to decide on organ donation matters on behalf of the deceased when the deceased had not taken any initiative at all to do so, throughout his/her lifetime. There is a possibility that the reason why the deceased remained silent about their wishes was that they had never intended to become an organ donor in the first place; so, as this idea of donating organs had never been considered, how could we expect this wish to be shared with others? Therefore, the researcher prefers to maintain the liberty that it is upon each individual to have full power and authority over his/her own body in order to decide what is best for him/her during his/her lifetime and after death. Whether or not his/her organs should be donated is exclusively a private matter that must be decided by that particular person alone, unless any representatives have been officially appointed to act on his/her behalf.

Analogically, when a person is still alive, their views are respected and they are given full freedom to consent, choose and decide in matters relating to their own wellbeing, so why should we disrespect their wishes and beliefs once they have died, even though they are still the topic under discussion, particularly on what will happen to their own body after their death? Therefore, the involvement of relatives in organ donation matters should only be superficial, which includes being informed and notified before any organs are removed from the deceased's body for organ donation purposes, particularly in cases where the deceased had clearly expressed their intentions to donate organs. Nevertheless, this should not be taken to the extent of allowing them to interfere and decide on something that might never have been intended by the deceased during their lifetime. The consent of a competent person should carry full and binding authority for the removal of organs for donation⁶⁰⁴. "Full" would mean that, if someone has consented to donate

⁶⁰³ Tymstra TJ, Heyink JW, Pruijm J and Sloof MJH, 'Experience of Bereaved Relatives Who granted or Refused Permission for Organ Donation', (1992) *Family Practice*, Vol.9, No.2, 141-144, p.143.

⁶⁰⁴ Eike-Henner Kluge, 'Decisions About Organ Donation Should Rest With Potential Donors, Not Next of Kin', (1997) 157 *Can Med Assoc*, 160-160, p.160

organs, no-one else needs to be asked for permission to remove them⁶⁰⁵; “binding” would mean that no-one else may overrule the consent of the donor and substitute his or her own wishes⁶⁰⁶.

According to the Chairman of the National Fatwa Council of Malaysia, Abdul Shukor Hj. Hussein, it is the individual person him/herself who has the most rights to decide the whereabouts of his/her body during his/her lifetime and after death.⁶⁰⁷ However, it is preferable that, only in cases where both individual instructions and family members are unavailable would it then be fair and acceptable to automatically shift the right of control over the cadaver to the state. So, here, the state will act as the deceased’s representative and subsequently decide who may benefit from the organ donation⁶⁰⁸. However, it is advised that the state only be allowed to decide upon and take the organs if the situation is extremely urgent, justifying its decision to do so. And because consent is totally significant in any organ donation procedure, the researcher disagrees with the concept of mandatory cadaver organ procurement, where viable organs from recently deceased patients will be mandatorily procured, despite any protests from the patient before death, or his/her family⁶⁰⁹. Procuring organs through this system will definitely eliminate the spirit of donating, as it is coercive in nature and overrides the patient’s or the family’s autonomy. So, as organ donation is considered a noble and generous act, it must definitely be free from such harshness and compulsion.

The same restrictions should also apply to situations where families are allowed to overrule decisions that have already been made by the deceased during his/her lifetime. For example, if the deceased had already registered as an organ donor during his/her lifetime the family consequently must no longer be allowed to overrule this decision. If families are still allowed to do so, it seems that we are committing an injustice and disrespecting the deceased’s decision and wishes. The researcher completely agrees with

⁶⁰⁵ *Ibid*

⁶⁰⁶ *Ibid*

⁶⁰⁷ Interview on 13th. February 2009, 4.30pm at University Science Islam Malaysia.

⁶⁰⁸ Emson. H.E, ‘ It Is Immoral To Require Consent For Cadaver Organ Donation’, (2003) 29 *Journal Medical Ethics*, 125-127

⁶⁰⁹ Thomas D. Harter, ‘Overcoming The Organ Shortage : Failing Means and Radical Reform’, (2008) HEC Forum 20 (2), 155-182, p.156

Ferguson, who argues that, since we can give out all our goods to whomever we specify after death, and there is no involvement of the family or anyone else in doing so, why should we now allow our family the entitlement to deny our wishes to donate our own organs⁶¹⁰? Therefore, any interference by the relatives and next of kin on organ donation matters involving cadavers should be revised and, preferably, terminated.

Perhaps some might consequently argue that, by revoking the power and authority given to these relatives, the problem of organ shortage would become more serious and threatening, as fewer organs would be procured. Indeed, that prediction might come true; however, if all sane persons attaining the age of majority are provided with a wider opportunity to register as organ donors continuously, this might balance the situation. For example, when a person is asked whether they would like to become an organ donor each and every time they intend to renew their driving license or receive medical treatment at clinics, this would indirectly have an impact on their way of thinking and their perceptions of organ donation. Although they might not register as an organ donor immediately, they would at least be given the chance to gain awareness about organ donation activities taking place, ask questions if they have any doubts about it and appreciate the opportunity they have to help save other people's lives. At least organ donation would not be such an alien matter for them and they would be able to see the benefits of registering as an organ donor. And later, if they eventually decide to become one, they must be provided with all the assistance and facilities to do so, within a pleasant and simple registration system. However, if they decide to refuse such commitments, we must respect their wishes and never let anybody else override their decision by allowing others to decide on their behalf. Perhaps it would be sounder to assume that those who have not registered themselves are to be treated as persons not willing to donate organs and no other person should have equivalent authority to decide for them, unless they have formally appointed a representative to manage their affairs post mortem.

⁶¹⁰ Colin Ferguson, 'Shouldn't Be a Family Affair', (2009) *BMJ*, 338:b2011

Nonetheless, informing the deceased's family about the intention to donate organs is important to ensure a successful donation taking place later⁶¹¹. In so doing, this reflects the importance of family ties and shows respect to our loved ones. Moreover, informing our families about our wish to become an organ donor will indirectly make things easier, especially when the actual time comes to procure the organs. This is because they are already aware of the deceased's wishes and are emotionally prepared to have the organ donation procedures take place accordingly. All this will definitely simplify the management of the deceased's body. Additionally, these cadaveric donations must also be made non-directed. They must maintain their anonymity to ensure fairness to everybody and build up the public's trust in transplant centres⁶¹².

5.5 DO THE SICK HAVE RIGHTS OVER CADAVER ORGANS?

As mentioned earlier, the state might be granted powers to decide on behalf of the deceased, particularly in urgent situations, so does this entail a position where the sick could demand rights over these cadaveric organs? This might seem medically desirable, but ethically it violates individual autonomy, and the special relation between humans and their bodies, which renders it morally unjustifiable⁶¹³. Allowing this would indirectly mean that those patients who are sick due to organ failure can simply demand coercive transfer of organs by the state from those who have been declared dead even without the deceased's express consent while they were still alive. Applying this would also violate something essential to humans as we are constituted by our bodies and stand in a special relation to them, a relation that is deeply significant for the value of our lives. So, the manner in which our bodies are treated after we die commands respect and places deontological constraints on what others can or cannot do to our bodies⁶¹⁴.

⁶¹¹ Teresa J Shafer, 'Improving Relatives' Consent To Organ Donation', (2009) *BMJ*; 338:b701

⁶¹² Aaron Spital, 'Should People Who Donate A Kidney To A Stranger Be Permitted To Choose Their Recipients? Views of The United States Public', (2003), Vol.76, No.8, 1252-1256, p.1255

⁶¹³ Glannon, G. 'Do the sick have a right to cadaveric organs?' *J Med Ethics* 2003;29: 153-156

⁶¹⁴ *Ibid.*

Moreover, if the sick did have such a right, then it would result in unfair consequences, especially for those who had expressed an interest in bodily integrity after death⁶¹⁵. Due to these arguments, it is agreed that the sick should never be awarded such rights to cadaveric organs. And even if the state should assume the authority to decide on organ donation matters, this must only be applicable in exceptionally urgent cases where such acts can be medically and morally justified. However, in cases where clear objections have been made by the deceased, organ donation must never proceed.

5.6 WHY NOT PRESUMED CONSENT IN MALAYSIA?

It is now clear that cadaveric donation could possibly be the answer to organ shortage problems; nevertheless, this does not imply that it is best achieved by applying the opting out system as often suggested, even in Malaysia⁶¹⁶. Moreover, no serious action has been taken to further foresee its potential application in Malaysia or to anticipate its acceptance by the local people. Perhaps the fact that organs could be automatically procured after one's death while consent is presumed to be in existence after no objection is raised seems interestingly suitable for fulfilling the aim of obtaining as many organs as possible. However, although the opting-out system works successfully in some countries, it may not necessarily do the same in Malaysia.

Being a multiracial country, Malaysia must consider its diverse culture and religions practised before accepting any suggestions for implementation. Based on the findings of this study, from the total of 482 respondents, 37.3% (180 respondents) totally rejected the opting-out system and preferred to stick with the opting-in system, although 35.7% (172 respondents) positively accepted it. The remaining 27.0% (130 respondents) could not decide whether they wanted to accept the suggested opting-out system or not.

⁶¹⁵ *Ibid.*

⁶¹⁶ Puteri Nemie Kassim, 'Organ Transplantation in Malaysia: A Need for a Comprehensive Legal Regime', (March 2005), 24(1) *Med Law*, 173-189.

The results obtained did not reflect sufficient evidence that Malaysians are keen to change towards the opting-out system, as only 172 respondents were in favour of it. The researcher personally believes that the change to the opting-out system is still not necessary. Even with the existing opting-in system, we could actually generate a greater number of potential organ donors if its application is maximised accordingly. With the current situation and facilities available in Malaysia, there is much doubt over whether even the opting-out system could be the solution to the organ shortage problems. Basically, Malaysia is not yet prepared to shift to the opting-out system as the existing resources and facilities are still limited and developing. The researcher totally supports the opinion given by Dr. Ghazali Ahmad who mentioned that, to apply the opting-out system, the country's mechanisms for spreading information and obtaining feedback from the citizens must first be excellent and very well-developed⁶¹⁷. If informative communications and mass media facilities still have massive limitations in trying to reach everybody, fair distribution of knowledge and correct information about the subject matter is quite impossible to achieve, especially within a short period of time. Even in the UK, it is predicted that a minimum period of three years following enactment of the legislation would be necessary to convincingly ensure that every single person was been contacted and made aware of the new system were it to be changed⁶¹⁸. So, as Malaysia still has limited access to information, it would definitely be unfair to simply assume that everybody is willing to donate their organs to help save other people's lives.

The geographical factors of Malaysia itself also contribute, as there are parts of the country which are still considered rural areas and are situated far from towns and development, particularly those located in the Sabah and Sarawak states. Many places within these two states are located far from one another, greatly restricting travel and communication. Some places are only reachable by plane and it would be almost impossible to gather everybody in a certain place to give information and explanations on organ transplantation in only a few attempts. If, by any chance, the opting-out system

⁶¹⁷ Interview conducted on 12 February 2008, at 2.30-5.30 pm at the Kuala Lumpur General Hospital. Dr Ghazali is a Consultant and Head of the Department of Nephrology at the Kuala Lumpur General Hospital, Malaysia

⁶¹⁸ *The Potential Impact of an Opt Out System for Organ Donation in the UK. An Independent Report from the Organ Donation Taskforce*, 2009. para 10.10, p.20. www.dh.gov.uk. Viewed on 20 January 2009.

were to be applied, it would only be fair to the people if the government ensured and provided a massive distribution of information related to the matter, including having a personal, individual approach by transplant officials and staff, and even using computers and Internet access⁶¹⁹.

However, it is not just an explanation of how the opting-out system operates that is essential; the authorities also need to ensure people's understanding of the matter and obtain their feedback and initial response on whether they would agree with it or not. To further support the importance of having a good communication system to disseminate information to the public, we can draw upon an example from the USA; interestingly, even in a developed country such as the United States of America, the problem of communicating information to the people still exists.

According to the findings from Michele Goodwin's research in two different surveys, 90% of the participants from a survey administered to 15 local government officials in Lexington, Kentucky, were unaware that presumed consent laws were already applied in their state. Only 1 of the 15 people (6.6%) surveyed in the Mayor's office was aware of the presumed consent law applied in Kentucky. In another survey with 100 participants selected from community leaders, clergy, college students and community advocates in Southern states such as Kentucky, Arkansas, Maryland, Alabama, Tennessee and North Carolina, only 5 of the 100 people (5%) had ever heard of presumed consent laws even though that particular law had been applied to them for quite some time⁶²⁰. Imagine how they would feel and respond once they knew that organs from any of their deceased relatives or friends could be taken away upon their death. Or, even worse, at the funeral of the deceased, they might discover the fact that organs from their beloved deceased had already been harvested and that nothing could be done to stop it as it would be too late. The researcher believes that, in this situation, the deceased family members would be in a more stressful situation than if they had been asked whether organ donation should be considered or not. They would presumably feel angry and very disappointed, especially if

⁶¹⁹ *Ibid.*

⁶²⁰ Goodwin, Michele. *Black Markets The Supply and Demand of Body Parts*. (The United States of America, Cambridge University Press, 2006) pp.131-132.

they initially had no intention at all of donating their own organs or those of their family members. In any country that implements the opting-out system fairly, it must be ensured that the people totally understand how the system operates and that they are aware of their rights to opt out of the system if they are not willing to become organ donors upon their death. Being totally ignorant about the system in the first place, how can they be expected to exercise their rights and opt out if they actually do not wish to donate their organs? Consequently, any lack of information supplied to these people is actually an infringement of their right to make an informed choice on whether to become an organ donor or not. This also negatively leads to a lack of respect for individual rights and fails to secure a valid informed consent, as is ethically required.

In an opting-out system, the government will also need to provide facilities to enable people to opt out of the system if they do not wish to become organ donors. Dr. Ghazali also suggested that the government should allow people to claim travelling expenses to reach designated points to opt out of the system, especially for those staying far away from these opt-out centres and for whom travelling is considered very expensive. As an alternative to this, the government is advised to consider providing opting-out facilities at all local health centres and government clinics which are available in every district, to make it easier for the locals to opt out. Another suggestion is to provide transplant officers who could approach all individuals and seek their consent and response to the suggested system. However, in short, Dr Ghazali still believes that Malaysia is not at all ready for this drastic change and that we have not yet fully maximised our efforts within the existing opting-in system.

Dr. Zakaria Zahari, on the other hand, believes that opting-out might be the answer to the current organ shortage problem, but he also agreed that Malaysia is not ready to implement such a system now⁶²¹. He justified the proposed opting-out system because, once people die, they actually no longer possess rights nor own their bodies. He also supported the idea that the state should have the right to retain people's bodies and body

⁶²¹ Dr Zakaria is the Head Department of Paediatric Surgery, at the Paediatric Institute of Kuala Lumpur General Hospital. The Interview was conducted on 18th. January 2008, 2.15-2.45pm at the Paediatric Institute, Kuala Lumpur General Hospital.

parts after death takes place. Moreover, this would be done for the benefit of others. It might consequently be true that more organs could be harvested as a result of applying the suggested opting-out system but materially Malaysia would not be able to cope with such a drastic increase for the time being. Dr. Zakaria, who is also a specialist in liver transplant procedures, told how his liver transplant team can only proceed with 50 cases of liver transplantation per year. So, basically, they would only need about 50 livers per year for these procedures. That is already the maximum number of cases that they could currently attend to due to constraints in facilities and manpower. Dr. Zakaria further emphasized that, although a successful transplant procedure would solve one problem, at the same time another set of problems would start to arise. “It is not just a matter of replacing and transplanting the organs, but further intensive care is crucially required to ensure rejection and other possible complications do not take place” he added. Finally, even if presumed consent were applied, the lack of infrastructure needed to keep a registry of recipients and the manpower to notify and prepare them when an organ becomes available would still not provide a satisfactory and efficient system even though there is a transplant waiting list in existence.⁶²².

The opting-out system is often said to relieve the grieving family members of the burden of having to decide on organ donation for the deceased, although this is actually only a presumption. The deceased family would not need to be prompted by the organ procurement staff asking for their consent to utilise the organs of their deceased family member, which could obviously be hard, particularly in a situation where the family is striving to cope with the loss of their loved one.

There are even countries that have attempted to shift to the opting-out system but ultimately without success. Brazil is a good example of a country which abolished the presumed consent law⁶²³; this was initially passed in February 1997⁶²⁴, whereupon

⁶²² Interview with Sister Jamaliah Kario, Programme Co-ordinator, National Transplant Registry, Kuala Lumpur General Hospital, 7th. January 2008, 2-5pm, at the National Transplant Registry, Kuala Lumpur General Hospital.

⁶²³ Amber Rithalia, Sara Suekarran, Lindsey Myers and Amanda Sowden, ‘Impact of Presumed Consent for Organ Donation on Donation Rates : A Systematic Review’, (2009) *BMJ* 338:a3162

consent was recorded on an ID card or driving license⁶²⁵. Even before the presumed consent law was passed, it was highly criticised especially by medical organisations such as the Brazilian Medical Association and the Federal Council of Medicine⁶²⁶. However, in practice the doctors continued to seek families' consent and were unwilling to remove organs, although the law demanded they do so, until family consent was obtained⁶²⁷. This led the Brazil Government to add a new paragraph to the law, stating that doctors should get permission from relatives to remove organs. The paragraph also mentioned that the will of the father of the deceased person should prevail and that, in his absence, the doctors should ask other family members according to their rank, starting from mother, son or daughter, then lastly the spouse, for consent before organs are removed⁶²⁸. Unfortunately, later, in 1998, the law had to be repealed, principally due to claims of mistrust by government and accusations of body-snatching⁶²⁹.

The recent Independent Organ Donation Taskforce in the UK finally concluded that it could not recommend the introduction of the opting-out system in the UK at the present time⁶³⁰. The three main objectives of the taskforce were to:

- i) Measure what might be required to introduce an opting-out system in the UK;
- ii) Check whether the opting-out system would really increase the number of organ donors in the UK; and
- iii) Consider the public's attitude towards the opting-out system.

The Taskforce believed that, were such a system to be applied, it would undermine the concept of treating organ donations as precious gifts, erode trust in NHS professionals and government, and impact negatively on organ donation numbers. The new system would be financially costly to implement, and there was also no guarantee that changing the system alone would then increase the number of donated organs, thus leaving the

⁶²⁴ Caudio Csillag. "Brazil Abolishes "Presumed Consent" in Organ Donation". *The Lancet*, Volume 352, Issue 9137, 24 October 1998, pg 1367.

⁶²⁵ *The Potential Impact of an Opt Out System for Organ Donation in the UK. An Independent Report from the Organ Donation Taskforce*, 2009. para 11.5, p.23. www.dh.gov.uk. Viewed on 20 January 2009.

⁶²⁶ Caudio Csillag. "Brazil Abolishes "Presumed Consent" in Organ Donation". *The Lancet*, Volume 352, Issue 9137, 24 October 1998, pg 1367.

⁶²⁷ *Ibid.*

⁶²⁸ *Ibid.*

⁶²⁹ *The Potential Impact of an Opt Out System for Organ Donation in the UK. An Independent Report from the Organ Donation Taskforce*, 2009. para 11.5, p.23. www.dh.gov.uk. Viewed on 20 January 2009.

⁶³⁰ *Ibid.*, p.34

organ shortage dilemma unresolved. Therefore, the Taskforce recommended that the opting-in system be maintained in the UK and that a review to adopt the opting-out system only be made after another five years, should no improvements be noted.

Similarly, in the United States, one of the highest annual figures for cadaveric donors was observed where direct consent of the deceased or his/her family is required by law⁶³¹. This highlighted the fact that wide dissemination of information and a general social acceptance of organ donation are more important for achieving a high donation rate than having the presumed consent system⁶³². Considering all the facts and arguments above, Malaysia too would seem best advised to retain the same opting-in system while trying its best to improve its weaknesses and maximizing the usage of potential cadaver donors, particularly those considered brain-dead after being involved in severe road traffic accidents.

CONCLUSION

Facing the challenge to obtain more organs to solve the organ shortage problem, it is comforting to know that cadaveric donations are the best alternative available. Therefore, more effort must be geared to fully utilising these resources that we already naturally possess, as every organ missed represents not only a potential death or continued disability but also a drain on society's health resources⁶³³. The remaining issue is: from where can these potential cadaveric organs be obtained? The answer will be discussed in the following chapter.

⁶³¹ W'odarczyk, Z 'Legal Aspects of Organ and Tissue Transplantation', (2003) 35 *Transplantation Proceedings*, 1202-1203, p.1202

⁶³² *Ibid*

⁶³³ Eike-Henner Kluge, 'Decisions About Organ Donation Should Rest With Potential Donors, Not Next of Kin', (1997) 157 *Can Med Assoc*, 160-160, p.161

CHAPTER 6

ROAD TRAFFIC ACCIDENTS IN MALAYSIA

INTRODUCTION

Maximising the use of cadaveric organs could be the potential answer to solve organ shortage problems. These resources could best come from road traffic accident victims, as these accidents occur every day. These fatalities are a tragic loss and devastating; however, by allowing organs from these deceased persons to be donated, their sudden deaths could be rendered more meaningful by giving hope to others. This chapter will highlight the severity of road traffic accidents taking place, the factors causing them and finally suggest how this problem could become a potential source of the much-needed supply of human organs, particularly in Malaysia.

6.1 THE HIDDEN EPIDEMIC

The World Health Organisation (WHO) considers death caused by road traffic accidents a “hidden epidemic”⁶³⁴. Traffic accident injuries are a major but neglected public health problem that requires concerted efforts for effective and sustainable prevention⁶³⁵. Each year, 1.26 million people are killed in road traffic accidents⁶³⁶ while 50 million more are injured, and these incidents mostly occur in developing countries⁶³⁷. The first study of global patterns of death by WHO, among people aged between 10 and 24, found that road traffic accidents are one of the major causes of mortality besides complications during pregnancy and childbirth, suicide, violence, HIV/AIDS and Tuberculosis (TB)⁶³⁸. Traffic accidents are the largest cause, accounting for 14% of male and 5% of female deaths, and

⁶³⁴ ‘Traffic Accidents Scar Latin America’s Roads’, (27 August 2005) www.thelancet.com, Vol.366.

⁶³⁵ Mohammadi, G, ‘Mobile Phone and Seat Belt Usage and its Impact on Road Accident Fatalities and Injuries in Southeast Iran’, (August 2009) *International Journal of Crashworthiness*, Vol.14, No.4, 309-314.

⁶³⁶ WHO Acts on Road Safety to Reverse Accident Trends’, (4 October 2003), *The Lancet*, Volume 362, Issue 9390, 1125.

⁶³⁷ ‘Accelerating Action on Road Safety’, (22 March 2008) www.thelancet.com, Vol. 371.

⁶³⁸ World Health Organisation, ‘Road Accidents, Suicide and Maternal Conditions are Leading Causes of Death in Young People, WHO-Supported Study of Global Mortality Patterns Show 2.6 Million Young People Die Each Year’, http://www.who.int/mediacentre/news/releases/2009/adolescent_mortality_20090911/en/print.html, viewed on 14 September 2009.

it is suspected that the increase in availability of motor vehicles may be the cause of such a rise in road traffic injuries⁶³⁹. In the USA, road traffic accidents are considered the fifth most common cause of death among those aged below 35 years⁶⁴⁰. All this is largely related to the growth in population and the increase of the vehicle fleet, including more road networks being constructed⁶⁴¹.

Undeniably, rapid urbanisation and motorisation results in increasing exposure to determinants of road traffic injuries, such as unsafe public transportation, higher speeds and a diverse vehicle mix on the roads⁶⁴². By 2020, if appropriate action is not taken, road traffic accidents could be the third leading contributor to the global burden of disease and injury⁶⁴³, with a predicted 60% rise in traffic-related fatalities expected to take place worldwide between 2000 and 2020⁶⁴⁴. This is indeed a liability to society as these people, particularly the young ones, are supposed to become productive members of society, yet their potential is wasted by their early deaths that could actually be avoided if necessary preventive steps were taken.

The personal and social impact of death and disability related to road traffic injuries, including the sufferings of individuals and their families, is massive and difficult to capture in quantitative terms⁶⁴⁵. In some cases, where death does not occur, the victims are still left with severe injuries and disadvantages such as chronic disability, lifelong earning capacity lost, and education ended or interrupted; furthermore, their families have to take on the burden of caring for them due to their inflicted disabilities⁶⁴⁶. Road traffic

⁶³⁹ George C Patton, Carolyn Coffey, Susan M Sawyer, Russell M Viner et al, 'Global Patterns of Mortality in Young People : A Systematic Analysis of Population Health Data', (12 September 2009), *The Lancet*, Vol. 374, 881-892.

⁶⁴⁰ 'An Ounce of Prevention is Better Than the Best Trauma Care', (4 February 2006) www.thelancet.com, Vol. 367.

⁶⁴¹ Fareed M.A.Karim, 'Short Reports Road Traffic Accidents in Yemen', (September 2008) *International Journal of Injury Control and Safety Promotion*, Vol.15, No.3, 165-166.

⁶⁴² Adnan A Hyder and Margie Peden, 'Inequality and Road-Traffic Injuries: Call for Action', (2003) *The Lancet*, Vol.362, December 20/27, 2034-2035, www.thelancet.com

⁶⁴³ World Health Organisation, *World Health Report 2002: Reducing Risks, Promoting Healthy Life*. Geneva: World Health Organisation, 2002.

⁶⁴⁴ 'The Hidden Epidemic of Road-Traffic Injuries', (17 June 2006) www.thelancet.com, Vol.367, 1954

⁶⁴⁵ Adnan A Hyder and Margie Peden, 'Inequality and Road-Traffic Injuries: Call for Action', (2003) *The Lancet*, Vol.362, December 20/27, 2034-2035.

⁶⁴⁶ 'On the Road: Accidents That Should Not Happen', (April 2007) www.thelancet.com, Vol.369.

injuries are also responsible for economic losses of 1-2% of the annual gross domestic product, especially in low- and middle-income countries⁶⁴⁷. The international statistics and situations above actually reflect the same trend in Malaysia, where road traffic fatalities are also a very common phenomenon. They are included within the top 10 causes of death occurring to Malaysians⁶⁴⁸ and injuries sustained from them remain the most frequent cause of death, accounting for 60% of the brain deaths and 40% of the cardiac deaths reported⁶⁴⁹.

6.2 ROAD TRAFFIC ACCIDENTS IN MALAYSIA

Road accidents seem to happen almost every minute, be they light or serious, involving both public transport and private vehicles, such as buses, cars, motorcycles and even pedestrians. The situation becomes worse during festive seasons when these road casualties double in number, as everybody seems to be in a hurry to reach their destination. As members of a multiracial country, Malaysians celebrate several big occasions each year, such as *Eid Al Fitr* and *Eid Al Adha* for the Muslims, Chinese New Year and *Chap Goh Mei* for the Chinese and *Deepavali* as well as *Thaipussam* for the Indians. All these religious celebrations are important for each particular race and these special days are declared public holidays throughout the country. In practice, it is common for all the races to celebrate together in a spirit of unity and harmony while many also take these opportunities to visit and celebrate with family and friends.

However, although festive seasons should actually be a time of joy and happiness, they are often a time when the number of road traffic accidents increases. Thus, they are a remorseful time for some people. For example, on 20th September 2009 alone, while all Muslims were celebrating the first day of *Eid Al Fitr*, 31 deaths resulted from a massive

⁶⁴⁷ Peden M and Hyder AA, 'Road-Traffic Injuries are a Global Public Health Problem', (2000) *British Medical Journal*, 324:1153.

⁶⁴⁸ 'Mortality Country Fact Sheet 2006, Malaysia', World Health Organisation, http://www.who.int/whois/mort/profiles/mort_wpro_mys_malaysia.pdf. Viewed on 11 September 2009.

⁶⁴⁹ Lela Yasmin Mansor. Fourth Report of the National Transplant Registry 2007, (Kuala Lumpur, National Transplant Registry, 2007), p.171

total of 1,031 road accidents taking place all over Malaysia⁶⁵⁰. In this year, the “20th Ops Sikap” campaign⁶⁵¹, which lasted from 13 September until 27 September 2009, and was held in conjunction with the *Eid* celebrations, disappointingly recorded a total of 261 deaths⁶⁵² taking place with an average of 17.4 deaths each day, all caused by severe road traffic accidents⁶⁵³. Generally, about 60% of the fatalities involved motorcyclists and their pillion passengers⁶⁵⁴. This massive total makes this year’s road fatalities the highest since the “Ops Sikap” campaign was introduced in 2001⁶⁵⁵. In the previous year’s “Ops Sikap” campaign, only 170 deaths were recorded during the 20-day campaign⁶⁵⁶, which indicates that the problem is getting worse each year.

According to Suret Singh, Chairman of the Department of Road Safety Malaysia, most of the accidents are caused by speeding, particularly during rainy weather, and by drivers who were too tired or sleepy due to long-distance driving⁶⁵⁷. This explanation is justifiable as, during festive seasons, many people are travelling back to their home towns, which normally involves long, tiring hours of driving. Undeniably, prolonged periods of driving under monotonous conditions leads to a continuous reduction in vigilance and could possibly cause accidents⁶⁵⁸. This increase in fatalities does not really come as a surprise as it matches the statistics from the Royal Police Force Malaysia from 2002 until 2007⁶⁵⁹, which indicate that there is always an increase in the number of road

⁶⁵⁰ Umavathi Ramayan, ‘31 Korban Nahas Jalan Raya Semalam’, *Utusan Online*, 22 September 2009, www.utusanonline.com, viewed on 22 September 2009.

⁶⁵¹ These *Ops Sikap* Campaigns are conducted by the Royal Police Force Malaysia to monitor and reduce accident rates particularly during festive seasons.

⁶⁵² ‘Korban Jalan Raya Meningkatkan 261 Hari Terakhir Ops Sikap’, *Berita Harian Online*, 28 September 2009, <http://www.bharian.com.my/>, Viewed on 28 September 2009.

⁶⁵³ Umavathi Ramayah, ‘Ops Sikap Gagal?’, *Utusan Online*, 29 September 2009, www.utusan.com, Viewed on 29 September 2009.

⁶⁵⁴ *Ibid*

⁶⁵⁵ Bernama, ‘Mengantuk , Hujan, Pandu Laju Punca Kemalangan Maut Meningkatkan : JKJR’, 25 September 2009, *Berita Harian Online*, www.bharian.com.my/, viewed on 25 September 2009

⁶⁵⁶ ‘Apabila Pemandu Sedia Bayar Saman Dan ‘Sedia Mati’ di Jalan Raya’, *Utusan Online*, 28 September 2009, www.utusan.com, Viewed on 28 September 2009.

⁶⁵⁷ Bernama, ‘Mengantuk , Hujan, Pandu Laju Punca Kemalangan Maut Meningkatkan : JKJR’, 25 September 2009, *Berita Harian Online*, www.bharian.com.my/, viewed on 25 September 2009.

⁶⁵⁸ Eike A. Schmidta, Michael Schrauf, Micheal Simona , Martin Fritzschea, Axel Buchnerb and Wilhelm E. Kincsesa, ‘Drivers’ Misjudgement of Vigilance State During Prolonged Monotonous Daytime Driving’, (2009) 41 *Accident Analysis and Prevention*, 1087-1093.

⁶⁵⁹ Statistics on Road Traffic Accidents and Deaths, <http://www.rmp.gov.my/> Official Website of the Royal Police Malaysia, viewed on 10 September 2009

traffic accidents reported every single year. For instance, in 2002 the total was 279,711, rising to 298,653 the following year⁶⁶⁰. Surprisingly, in 2007 the total had already reached a figure of 363,319 for that year alone.

From these figures, year after year, thousands of precious lives are lost in these serious accidents. In 2002, 5,891 lives were lost, followed by 6,286 in 2003. Recently, in 2007, another 6,282 precious lives were lost, meaning that the overall average number of people dying from road accidents in Malaysia is around 6,200 persons per year⁶⁶¹. The same statistics also report that the highest number of deaths involves motorcyclists. For instance, out of 5,672 lives lost in road traffic accidents in 2007, 3,197 were actually motorcyclists. This total was followed by 697 car drivers and 636 pedestrians⁶⁶². In 2008, 3,898 deaths were reported and 60% of this total involved motorcyclists and their pillion passengers⁶⁶³. According to the Institute of Research of the Road Safety Department Malaysia (MIROS), 58% of the motorcyclists died from severe head injuries⁶⁶⁴. That is why motorcyclists are urged to avoid travelling at night⁶⁶⁵, particularly when vision is limited and they might not be seen clearly by other road users, making them even more vulnerable to road accidents. Moreover, the hours of darkness are not only a time of reduced visibility and lighting but are also a time, quite unlike mornings and afternoons, when different groups of road users are present, travelling for different reasons and in different ways⁶⁶⁶. Alternatively, motorcyclists are encouraged to use public transport, particularly for long-distance travel.

⁶⁶⁰ *Ibid*

⁶⁶¹ *Ibid*

⁶⁶² *Ibid*

⁶⁶³ Ong Tee Keat, Speech Text of the Minister of Road Transport Department at the Launching of the Wearing Children's Helmet Campaign in Selangor, http://www.panducermat.org.my/Teks_ucapan_Menteri_Pengangkutan_Sempena_Majlis_Perasmian_Kempen_Topi_Keledar_Kanak-kanak.html, viewed on 10 September 2009

⁶⁶⁴ *Ibid*

⁶⁶⁵ 'Menjelang Musim Perayaan Hari Raya Aidil Fitri 2009 Masyarakat Malaysia Diseru Bersatu untuk MUFORS 090909 Bagi Meningkatkan Keselamatan Jalan Raya', <http://www.panducermat.org.my>, viewed on 10 September 2009.

⁶⁶⁶ Ghorbanali Mohammadi, 'The Pattern of Fatalities by Age, Seat Belt Usage and Time of Day on Road Accidents', (March 2009) *International Journal of Injury Control and Safety Promotion*, Vol. 16, No.1, 27-33.

For accidents involving other vehicles, the underlying cause always points back to the driver's own negative attitude (67%), surrounding factors (28%) and technical problems (5%)⁶⁶⁷. For example, statistics from the Royal Police Malaysia show that the driver's attitude contributes the most, as 30.7% of accidents are caused by reckless driving and overtaking, 26.5% are due to excessive speeding, 8.1% result from entering and exiting junctions negligently and, lastly, 6.3% result from drivers tailing the preceding vehicle too closely⁶⁶⁸. Surrounding factors include the condition and layout of the road itself⁶⁶⁹ which could be seen as either positive or negative. In some cases, the roads are not well-maintained, causing disruptions during driving, or the roadsides are too dark without proper lighting facilities⁶⁷⁰. Surprisingly, there are also cases where, because the roads are in perfect condition, there is a temptation to speed, although the Road Transport Act 1987 (Act 333) clearly spells out a term of imprisonment not exceeding five years, or fines not exceeding RM10, 000, or both, for committing any offence of reckless and dangerous driving causing the death of a person. If death is not caused, any act of reckless driving that causes danger to the public attracts, upon conviction, a fine not exceeding RM 6,000, or imprisonment for not more than three years, or both.⁶⁷¹ One possible reason why the public is not taking extra precautions to avoid road traffic accidents is because they do not treat road traffic accidents as a problem, unlike their attitudes towards other diseases such as HIV and TB⁶⁷². Because they are not regarded as

⁶⁶⁷ Mastura bt. Mohd Zain, 'Sikap Pemandu Punca Nahas Jalanraya', Institute of Islamic Understanding Malaysia, <http://www.ikim.gov.my>, 13 May 2008, viewed on 10 September 2009.

⁶⁶⁸ Azrina bt. Sobian, 'Sikap Sabar Asas Pemandu Berhemah', Institute of Islamic Understanding Malaysia, <http://www.ikim.gov.my>, 18 November 2005, viewed on 10 September 2009.

⁶⁶⁹ *Ibid*

⁶⁷⁰ Joseph Schatz, 'On the Road in Zambia', (9 August 2008) www.thelancet.com, Vol.372, 435-436.

⁶⁷¹ Section 41 (1) "Any person who drives a motor vehicle on a road recklessly or at a speed or in a manner which having regard to all the circumstances (including the nature, condition and size of the road, and the amount of traffic which is or might be expected to be on the road) is dangerous to the public, causes the death of any person shall be guilty of an offence and shall on conviction be liable to a fine not exceeding ten thousand ringgit or to imprisonment for a term not exceeding five years or to both.

(2) The court shall order particulars of any conviction under this section to be endorsed on any driving licence held by the person convicted.

Section 42. (1) Any person who drives a motor vehicle on a road recklessly or at a speed or in a manner which having regard to all the circumstances (including the nature, condition and size of the road and the amount of traffic which is or might be expected to be on the road) is dangerous to the public shall be guilty of an offence and shall on conviction be liable to a fine not exceeding six thousand ringgit or to imprisonment for a term not exceeding three years or to both and, in the case of a second or subsequent conviction, to a fine not exceeding ten thousand ringgit or to imprisonment for a term not exceeding five years or to both.

(2) The court shall order particulars of any conviction under this section to be endorsed on any driving licence held by the person convicted".

⁶⁷² Joseph Schatz, 'On the Road in Zambia', (9 August 2008), www.thelancet.com, Vol.372, 435-436.

a problem, they are not taken seriously, particularly in terms of preventing them from happening in the first place.

Another possible cause of accidents is that the transport and urban infrastructures are not set up to cater for the safety and needs of non-motorised road users⁶⁷³. For instance, pedestrians, cyclists, motorcyclists and their passengers have no other choice but to share road space with cars, buses, trucks and other large vehicles, putting them at high risk of being knocked down. To make things worse, most of the time these non-motorised road users rarely wear protection such as helmets and bright, fluorescent or reflective clothing to make others aware of their presence. Having many young and inexperienced drivers on the road could possibly contribute to this problem too⁶⁷⁴. Although excessive alcohol consumption is not the main cause of accidents in Malaysia, in contrast to the USA and the European Union where 30-50% of the traffic accidents are related to alcohol intake⁶⁷⁵, there are still a small number of cases where the drivers are drunk and later get involved in accidents⁶⁷⁶. Insufficient maintenance of the road network, inappropriate behaviour of the road users and lack of efficient and systematic enforcement are also common reasons contributing to the high rates of road traffic accidents in developing countries⁶⁷⁷, including Malaysia. Similarly, the usage of mobile phones is indeed an additional problem.

Although it is considered an offence to use mobile phones whilst driving, not many actually abide by this rule, unless they see a police officer nearby, for instance. This irresponsible act leads to road accidents due to inattention to the traffic, veering and

⁶⁷³ ‘On the Road: Accidents That Should Not Happen’, (April 2007), www.thelancet.com, Vol.369,

⁶⁷⁴ *Ibid*

⁶⁷⁵ Fabio Caputo, Franco Trevisani and Mauro Bernadi, ‘Alcohol Misuse and Traffic Accidents’, (10 February 2007), *The Lancet*, Vol.369, 463-464

⁶⁷⁶ Section 44 (1) of the Road Transport Act 1987 (Act 333)

“Any person who, when driving or attempting to drive a motor vehicle on a road or other public place, is under the influence of intoxicating liquor or a drug to such an extent as to be incapable of having proper control of such vehicle, shall be guilty of an offence and shall on conviction be liable to a fine not exceeding two thousand ringgit or to imprisonment for a term not exceeding six months and, in the case of a second or subsequent conviction, to a fine not exceeding four thousand ringgit or to imprisonment for a term not exceeding one year or to both”.

⁶⁷⁷ Ghorbanali Mohammadi, ‘The Pattern of Fatalities by Age, Seat Belt Usage and Time of Day on Road Accidents’, (March 2009), *International Journal of Injury Control and Safety Promotion*, Vol. 16, No.1, 27-33.

striking another vehicle, failure to give way, failure to stop, and running off the road⁶⁷⁸. Some have suggested an alternative of using hands-free phones rather than hand-held ones; however, there is no evidence that this might be safer as the effects of conversation using both hands-free and hand-held phones are rather similar, as one's concentration and focus on driving is affected in both situations, making it dangerous for the drivers in particular and other road users as well⁶⁷⁹. Therefore, the Ministry of Transport together with the Road Safety Department have initiated campaigns to create public awareness, particularly by showing advertisements where the experiences of those involved in and who have survived such road accidents are shared, including showing pictures of gruesome accident scenes⁶⁸⁰, to make the public value and appreciate their lives even more. However, while all this seems to have been unsuccessful, it is undeniable that a lot of precious lives are continuously being lost and, at the same time, plenty of usable organs are also being wasted. This scenario is indeed a big waste, especially when items as scarce and valuable as human organs are simply discarded due to a weakness in the existing organ donor registration system, which fails to provide opportunities for these organs to be automatically donated or received.

As suggested earlier, in chapter 5, those applying for or renewing driving licenses should be provided with the option to register as organ donors, while specifying which organs they are willing to donate so that, were they to be involved in a serious road traffic accident, their intentions would be clear. Moreover, this could also help the deceased's family members to know exactly how the deceased wanted his/her organs to be dealt with. The researcher strongly believes that, were this suggestion to be carried out, there would be a rise in the number of cadaveric organs available, particularly as the number of road accidents keeps increasing each year, despite all the efforts being made to reduce them. In this way, although the death is itself a loss to the bereaved family, they could

⁶⁷⁸ Mohammadi, G, 'Mobile Phone and Seat Belt Usage and its Impact on Road Accident Fatalities and Injuries in Southeast Iran', (August 2009) *International Journal of Crashworthiness*, Vol.14, No.4, 309-314.

⁶⁷⁹ Jan E. B. Tornros and Anne K. Bolling, 'Mobile Phone Use-Effects of Handheld and Hands free Phones on Driving Performance'. (2005) *Accident Analysis and Prevention*, Issue 5, Vol.37, 902-909

⁶⁸⁰ 'Menjelang Musim Perayaan Hari Raya Aidil Fitri 2009 Masyarakat Malaysia Diseru Bersatu Untuk MUFORS 090909 Bagi Meningkatkan Keselamatan Jalan Raya', <http://www.panducermat.org.my>, viewed on 10 September 2009.

still be proud to know that the deceased's 'gift of life' to those patients in need of his/her organs has at least saved another person's life.

6.3 ROAD TRAFFIC ACCIDENTS AS A SOLUTION FOR ORGAN SHORTAGE?

Many countries face the problem of organ shortages although, among the countries affected, there are different organ donation rates. This variation is caused by several factors including the rate of road traffic accidents taking place, the gun laws applicable, religious and cultural responses to death and the deceased body, and practical issues such as the availability of intensive care beds⁶⁸¹. Although Malaysia has a high rate of road traffic accidents, the number of organ donations taking place is not as high as might be expected. The fact that Malaysia has an estimated figure of 6,200 people dying from road accidents each year⁶⁸² makes it practical to utilise organs from road traffic accident victims, particularly those pronounced dead at the accident scene and those declared brain-dead soon afterwards. The situation that we have now leads to a massive number of cadaveric, brain-dead potential donors being available, which constitutes the largest pool of organs for transplantation⁶⁸³. Of course, having a high rate of fatal accident cases is not a good indicator for any country; however, if these potential organs are simply put to waste, the situation is made even worse. If this tragedy could at least be turned into something potentially beneficial to others, hopefully more lives could be saved while, at the same time, the deceased and their families would have the opportunity to make a final contribution to others.

According to Lela Yasmin, co-chairperson of the National Transplant Registry, Malaysia, as about 6,000 to 7,000 people are involved and die in serious road traffic accident cases

⁶⁸¹ Kennedy I, Sells, R A, Daar, A.S, Guttman R, Hoffenberg R, Lock M, Radcliffe-Richards J and Tilney N, 'The Case for "Presumed Consent" in Organ Donation', (1998) *The Lancet*, Vol 351, May 30, 1650-1652, p.1650

⁶⁸² Statistics on Road Traffic Accidents and Deaths, <http://www.rmp.gov.my/> Official Website of the Royal Police Malaysia, viewed on 10 September 2009

⁶⁸³ Ali Salim, George C. Velmahos, Carlos Brown, Howard Belzberg and Demetrios Demetriades, 'Aggressive Organ Donor Management Significantly Increases the Number of Organs Available for Transplantation', (2005) Volume 58, Number 5, *The Journal of TRAUMA Injury, Infection, and Critical Care*, 991-994.

every year, definitely many more lives could have been saved if only all these people had pledged themselves as organ donors⁶⁸⁴. Severe head injuries and cerebral haemorrhage commonly result from serious road accidents and have been reported to be the major cause of death among organ donors⁶⁸⁵. Many accident victims suffering from brain injuries subsequently experience brainstem death, which is a complex process resulting in multi-organ system failure and cardiovascular collapse if left untreated. In spite of cases where aggressive treatment is given, more than 25% of potential donors are still lost due to hemodynamic instability⁶⁸⁶. So, there is a huge opportunity for all these potential organs to be made available to help those desperately in need of these particular organs.

Coincidentally, in the researcher's recent study, a positive response was received from the respondents when they were asked whether they would allow the government of Malaysia to acquire their organs should they be involved in a serious road accident with no chance of survival at all. A total of 268 respondents, which represents 55.6% of the total, agreed with this idea. If this suggestion were to be actually carried out, thousands of lives could be saved; how many more could be saved if the result were to be viewed on a larger scale, representing the wishes of all Malaysians? Upon further dissection of the group that agreed to this idea, it was found that, within the non-registered organ donor group, 52.3% of them agreed with the idea while, among the organ donor group, a huge majority of 92.5% agreed with it.

These results suggest that existing registered organ donors are more likely to agree with this suggestion and perhaps this is associated with their self-awareness and individual altruism which strongly encourages them to donate their organs to others. The same study also revealed that, were the government to be allowed to procure organs from seriously injured road accident victims, both the non-donor respondents (89.1%) and donor respondents (75%) would have a similar preference for wanting their family's permission

⁶⁸⁴ Rabiatal Adawiyah Koh Abdullah, 'Menyelamatkan Nyawa Penerima Organ', Utusan Online, 26 July 2009. www.utusan.com. Viewed on 26 July 2009

⁶⁸⁵ Tymstra, T.J, Heyink, J.W, Pruijm, J, and Slooff, MJH, 'Experience of Bereaved Relatives Who Grant or Refused Permission for Organ Donation', (1992) Family Practice, Vol. 9, No. 2, Oxford University Press, Great Britain, 141-144.

⁶⁸⁶ Jenkins DH, Reilly PM, Schwab CW, 'Improving the Approach to Organ Donation: A Review, (1999) 23 *World J.Surg*, 644-649.

to be obtained first before their organs are procured. So, generally, a large majority of 88.0% (424 respondents) still insisted that their families be consulted first. The results show that there is a high rate of acceptance in allowing the Government of Malaysia to access and procure organs from these fatalities, provided consent is firstly obtained from their respective families. The above results also reflect the public's acknowledgement of the role of the family and this teaches us a valuable lesson that family influence must not be completely put aside, especially when it involves crucial, end-of-life, decision-making situations.

In resorting to brain-dead patients involved in road fatalities, where the deceased had expressly consented to organ donation, the organ donation procedures must proceed automatically. However, in cases where the victim cannot be identified even after thorough inquiries have been made or in cases where none of his/her family members can be traced, one possible solution is to exclude this group from becoming organ donors in the first instance. Therefore, no individual or authority would have the right to proceed with organ procurement procedures in these cases. However, if we still want to include this group as potential sources of organs, the other alternative available is to grant certain persons, such as the judge or the medical officer in charge, the authority to act on behalf of the deceased party. This procedure has already been practised in the USA, particularly in the states of California⁶⁸⁷, Pennsylvania⁶⁸⁸ and Texas⁶⁸⁹, where there are Anatomical Gifts Acts dealing specifically with this situation⁶⁹⁰.

In these states, the provisions allow that, after a diligent search for next of kin has failed, judges or medical examiners may grant permission for donation. However, substituted consent is limited in these special situations, as there are concerns that this method carries obvious risks, given that the social and medical history of the potential donor is unclear⁶⁹¹. But, to counter such claims, it can still be argued that, even in cases where the

⁶⁸⁷ State of California Health and Safety Code, Chapter 3.5, Uniform Anatomical Gift Act, 7150-7156.5

⁶⁸⁸ State of Pennsylvania Consolidated Statutes, Title 20, Chapter 86, 8611

⁶⁸⁹ Texas Health and Safety Code, Title 8, Chapter 693, 693.003

⁶⁹⁰ Gary K. Shen, Patricia A. Niles, Ken E. Richardson, 'Presumed Consent: The Case of The John Doe Donor', (15 March 2004) Vol.77, No.5, *Transplantation*, 792-793

⁶⁹¹ *Ibid*

next of kin can be identified, the same risk still exists, as there is no guarantee that they would possibly know everything about that particular potential donor, especially if they have been long-separated or lived different lives far apart from each other. Our main concern now is to add up the number of organs available and, surely, with our advances in science and technology, we should be able to take steps to eliminate these threatening risks perhaps through laboratory tests and experiments on the organs themselves.

Moreover, proceeding with brainstem-dead patients is easier than resorting to those who have experienced cardiac death since, in the former, the patients are already within the hospital settings and are normally maintained on cardio-respiratory support. So, once organ donation is agreed upon, respiratory support will be continued to ensure that the patient's organs are well maintained with sufficient oxygen supply as though he/she were still alive although, technically, all this is now performed and controlled by the breathing support machine. The patient is actually already dead because his/her brainstem is dead.

Compared to brainstem death patients, it is not possible to predict when and where cardiac death might take place, so it is impossible to be exact and carefully plan for it⁶⁹². Moreover, managing post-cardiac death donations is very complicated and requires a large amount of attention from medical staff⁶⁹³. To prepare and organize a post-cardiac death donation, the transplant team would normally require a few hours to undertake the necessary tests and set up their equipment. Consequently, this will simply prolong the dying process which would normally be stopped with the patient dying soon afterwards; it might now continue for up to 6 hours⁶⁹⁴. This practice may be culturally unacceptable in certain countries, even within the European Union, because it is considered labour-intensive, as mobile transplant teams must be rapidly set up to preserve the organs

⁶⁹² *Ibid.*, para 239, p.49.

⁶⁹³ Rafael Matesanz, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 240, p.49.

⁶⁹⁴ *Ibid.*, para 242, p.49.

whenever the need arises⁶⁹⁵. Even under the Mental Capacity Act 2005, it is very unclear whether this practice is lawful or not⁶⁹⁶.

As regards Malaysia, procurement of organs from post-cardiac death cases is allowed. However, since we have a large supply of brain-dead cases resulting from the high number of road fatalities, it would seem preferable to concentrate more on this type of potential donor. Moreover, donations after brainstem death are considered more straightforward, especially since the patients are already within a proper hospital setting, which allows immediate preparation for the intended transplantation to take place accordingly. Besides that, organs from this source are usually young and healthy⁶⁹⁷ due to the age limitation requirement for qualified vehicle drivers. Therefore, organ donation from such brain-dead cases must be promoted more to ensure that the existing supply is not simply put to waste, but generated further, to professionally solve our organ shortage problems. However, this suggestion is not equivalent to mandatory cadaver organ procurement, where any recently deceased patient with a viable transplant organ would have that organ mandatorily procured, despite any potential protests from patients prior to their death or from their surrogates⁶⁹⁸. Here all cases are optional and consent would still be obtained before any such organ donation could proceed. Glancing at our neighbouring country, Singapore, they too have been taking organs from their citizens and permanent residents who die in road accidents, except from those who have formally registered their objection with the Director of Medical Services⁶⁹⁹. Although they apply the opting-out system and the government is entitled to remove organs from donors who have not formally objected to the procedure, their doctors, in practice, still prefer to ask the families of the deceased for their consent and do usually respect their wishes⁷⁰⁰.

⁶⁹⁵ *Ibid*

⁶⁹⁶ O'Brien, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1: Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 240, p.49.

⁶⁹⁷ 'More Malaysians Pledge to Donate Their Organs', Malaysian Society of Transplantation, <http://www.mst.org.my/news/090209nst.html>, Viewed on 28 August 2009.

⁶⁹⁸ Thomas D. Harter, 'Overcoming the Organ Shortage: Failing Means and Radical Reform', (2008) *HEC Forum* 20(2): 155-182, p.156

⁶⁹⁹ Volker H. Schmit and Chee Han Lim, 'Organ Transplantation in Singapore: History, Problems, and Policies', (2004) 59 *Social Science & Medicine*, 2173-2182.

⁷⁰⁰ *Ibid*

Similarly, Iran has also resorted to road accident victims as it has one of the highest traffic fatality rates in the world, with 60% of the population being under 25 years of age⁷⁰¹.

For Malaysia to realize this solution, the government needs to train and provide more counsellors at hospitals to approach families of these accident victims, including seeking their consent to donate the organs of their deceased family members⁷⁰². Issues such as inadequate awareness by paramedics and doctors of the concept of brain death, late diagnosis of brain death cases and inadequate maintenance of brain death must no longer be obstacles⁷⁰³.

Concurrently, statistics from the Department of Statistics Malaysia estimates the total population in Malaysia to have reached 28.31 million in 2009, where 63.6% are represented by people aged between 15 and 64⁷⁰⁴. This shows that more than half of Malaysia's population is actually within the age limit suitable for becoming organ donors. Within this age group too, it is common to expect most of them to possess driving licences and to be using the roads daily. Therefore, since there are risks that they may get involved in road traffic accidents with either minor or major injuries, it would make a big difference if they were all registered as potential organ donors. These organs are also most suitable because those having driving licences are of a certain age group, meaning their organs would presumably be strong and healthy. In the researcher's previous study alone, 77.2% of the respondents possessed valid driving licenses and are actually on the roads daily. And, presumably, whenever we are on the roads either as a driver, passenger or even a pedestrian, there is always a risk of getting involved in a road accident. That is

⁷⁰¹ Official: Over 1.5 million dilapidated cars on Iranian Roads. Islamic Republic News Agency, Dec 4, 2002 referred in Raza M, and Hedayat, K.M, 'Some Sociocultural Aspects of Cadaver Organ Donation : Recent Rulings From Iran', 36 (2004), 2888-2890, p. 2889

⁷⁰² Jade Chan, 'Organ Donation a Gift of Life', 31 July 2009, The Star Online, <http://thestar.com.my/>, viewed on 10 September 2009.

⁷⁰³ Shaheen, F.A.M and Souqiyeh, M.Z, 'Increasing Organ Donation Rates From Muslim Donors : Lessons From A Successful Model', (2004) 36 *Transplantation Proceedings*, 1878-1880

⁷⁰⁴ 'Population by Age Group', Department of Statistics Malaysia Official Website, <http://www.statistics.gov.my/eng/index.php?option=com>, viewed on 11 September 2009.

why there is also a need for us to provide wider opportunities to register as organ donors, for instance while applying for or renewing driving licences.

According to Lee Lam Thye, Chairman of the Organ Donation Public Education Committee, as Malaysia records a tremendously high rate of death related to road accidents, she would no longer need to resort to living donors for the much-needed organs if just 10% of the overall number of fatalities decided to donate their organs or tissues.⁷⁰⁵ So, if this suggestion of utilising organs from accident victims were to be widely accepted in Malaysia, not only would the donating hospitals and transplant centres have to be well prepared, but the transportation system would also have to be enhanced to ensure that an efficient coordination and communication system was upgraded as well, especially to transport the harvesting teams, organs and potential organ recipients⁷⁰⁶.

In Spain there has been close collaboration between airports and aircraft systems to ensure rapid intercity transportation of organs⁷⁰⁷. Their national transplantation organization works with 40 airports nationwide and 11 of them run on a 24-hour basis, making it possible to make emergency journeys even at night or at daybreak, while ensuring that rapid coordination of all the transplantation team is made possible whenever necessary⁷⁰⁸.

Sufficient numbers of qualified paramedics in road emergency services are also needed to stabilize the patient's condition while attempting to preserve the organs longer⁷⁰⁹. Transplant coordinators should also be available at organ donation sites rather than just in particular transplant centres. The prime function of this local donation team is to detect, at the earliest stage possible, potential organ donors within intensive care units and to further monitor the medical progress through to a diagnosis of brain death that will

⁷⁰⁵ Noor Fazrina Kamal, 'Galak Derma Organ Melalui Media', Utusan Malaysia, 16 December 2008, p.7.

⁷⁰⁶ Rowinski W, Ostrowski K, Adadynski L. et al, 'Factors Limiting Renal Transplantation Program in Poland', (1996) 1 *Ann Transplant*, 18.

⁷⁰⁷ Xavier Bosch, 'Spain Celebrates Leading The World in Organ Donation', (1998) Vol 351, June 20, *THE LANCET*, 1868.

⁷⁰⁸ *Ibid*

⁷⁰⁹ Shaheen, F.A.M and M.Z. Souqiyeh, 'Increasing Organ Donation Rates From Muslim Donors : Lessons From A Successful Model', (2004) 36 *Transplantation Proceedings*, 1878-1880

subsequently lead to organ donation. However, while promoting this, it is equally important to reassure the people that they should never fear that their organs might be removed on any occasion before they are pronounced clinically dead. It must be guaranteed that, in any event of accidents, they will definitely receive sufficient, aggressive medical treatment to save their lives even if they have already consented to become organ donors upon their death. So, even though organs are needed to save many more lives, they will never be taken by sacrificing the life of another.

Another fact that needs to be seriously considered is the possibility that this source could dry up in the long term, especially when effective measures are eventually taken to reduce the number of road traffic accidents. It is undeniable that this source is not permanent and will decrease once accident death rates decline; however, for the time being, this suggestion is relevant and practical. For many years, a lot of effort has been made by the Government of Malaysia to reduce and control the number of road traffic accidents. However, all efforts seem useless and statistics from the Royal Police keep showing an increase in the number of road traffic accidents. Moreover, if we compare this solution to other suggestions such as resorting to organs from prisoners, for instance, the latter is even more controversial. Making use of prisoners as potential organ donors would definitely raise a lot of debatable issues, particularly as the prison environment has many coercive characteristics⁷¹⁰, including vulnerable prisoners being deprived of certain rights⁷¹¹. However, no such argument would arise when resorting to road accident victims, which is a simple and straightforward solution. There is indeed no coercion at all, as each donation is made voluntarily, with consent. Most important of all, potential organs donated from accident victims are plentiful and, particularly in Malaysia, the supply is currently sufficient to solve the organ shortage problem.

⁷¹⁰ Jeffrey P.Kahn, 'Three Views of Organ Procurement Policy : Moving Ahead or Giving Up?', (2003) *Kennedy Institute of Ethics Journal*, Vol.13, No.1, 45-50, p.46

⁷¹¹ Mills M A and Simmerling M, 'Prisoners as Organ Donors: Is it Worth the Effort? Is It Ethical, (2009) 41 *Transplantation Proceedings*, 23-24

CONCLUSION

Although it takes about 30 years for a high-income country to begin reversing the high death and injury rates that result from increased motorisation⁷¹², this fact should never discourage us from trying to reduce road accidents immediately. Everybody, including road builders, traffic wardens, traffic light setters, drivers, pedestrians, ambulance personnel, health carers and schoolteachers all have a part to play in preventing or treating road injuries⁷¹³. The police and Road Transport Department Malaysia, in particular, must ensure that road safety laws are obeyed, enforced strictly and equally applied to everybody. There should be no toleration at all in matters involving the safety of the public, particularly the road users, for whatever reasons. However, in cases where accidents still happen and result in death, it would make such a big difference if the deceased's organs were voluntarily donated to help save the lives of others, even though the deaths are, in themselves, devastating. So, even though these road traffic accidents are dreadful tragedies, we could at least still divert the consequences to contribute to helping other people. The only way is by encouraging road users to register as organ donors and persuade them to consent to donate their organs should they get involved in severe road accidents with no hope of recovery, while urging the bereaved families to respect this wish as well. It is of course painful to lose human lives but, at the same time, the organs of the deceased are also too precious to be simply put to waste.

⁷¹² Accelerating Action on Road Safety', (22 March 2008), *The Lancet*, Vol. 371, Issue 9617, p.960.

⁷¹³ Elizabeth Molyneux, 'Saving the Survivors', (24 February 2007), *The Lancet*, Vol.369, No.9522, p. 1591-1597.

CHAPTER 7

THE ISLAMIC PERSPECTIVE ON ORGAN TRANSPLANTATION AND OTHER RELATED ISSUES

INTRODUCTION

The impact of religious belief is powerful enough to influence the attitude and response of the public at large towards motivating people into accepting and consenting to organ transplantation activities⁷¹⁴. Religious beliefs can pattern their followers' perceptions and have always been a top priority consideration in accepting any forms of new technologies introduced. However, there is no particular religion which formally obliges one to donate or refuse organs, or that treats organ donation as a "societal resource" or a "religious duty"⁷¹⁵. This chapter will focus on the Islamic perspective on organ donation. Discussions on the basis of the Islamic rulings approving organ donation will be included while equally highlighting arguments put forward by minority Muslim scholars who are reluctant to accept it, either totally or partially. This chapter aims to clarify the doubts and explain how organ donation is actually permissible and approved by Islam, despite the reluctance and rejections expressed by a minority group of Islamic jurists. In the light of the views put forward, we will also see the position taken by Malaysia, which is guided by the rulings from the National Fatwa Council. Other related issues discussed include the Islamic view on organ trading, cadaver and living donations, the brain death concept and living wills. The suggestion to utilize victims of road traffic accident cases as a potential solution for organ shortage problems is also discussed in the light of recent Islamic rulings to determine its potential acceptance within the religious framework.

7.1 ISLAM AND ORGAN DONATION

Religious and cultural values of every population have a significant impact on health, education and social policies⁷¹⁶, which indirectly shows why these elements are very

⁷¹⁴ El-Shahat, Y.I.M, 'Islamic Viewpoint of Organ Transplantation' (1999) 31 *Transplantation Proceedings*, 3271-3274. p.3271

⁷¹⁵ Bruzzone, P, 'Religious Aspects of Organ Transplantation' (2008) 40 *Transplantation Proceedings*, 1064-1067. p.1064

⁷¹⁶ Hussein Rassool, G, 'The Crescent and Islam: Healing, Nursing and Spiritual Dimension. Some Considerations Towards an Understanding of the Islamic Perspectives on Caring' (2000) 32(6) *Journal of Advanced Nursing*, 1476-1484. p.1482

influential in organ transplantations practised today⁷¹⁷. Generally, all religions accept the practice of organ donation and transplantation⁷¹⁸ and are greatly concerned about the preservation, dignity and honour of human life. The Muslim community is, without exception, subject to this phenomenon too. The whole of Islamic medicine, throughout history until today, is related to Islam through the injunctions contained in the Quran and Sunnah⁷¹⁹, requiring Muslims to be concerned with and guided by ethics derived from the Islamic Law rather than by purely medical considerations⁷²⁰. Muslims are also sensitive to issues touching on their religion, especially when it involves decisions related to matters in their everyday lives. There is always a feeling of responsibility to protect and guard their religion in all circumstances and a desire to remain within the confines set by their own religion. Therefore, Islamic rules and teachings are the most important factors influencing both living and cadaver organ donation in most Muslim countries⁷²¹.

Muslims are concerned with the attitude of *Shariah* (Islamic Law) towards a particular treatment and would only agree to it if it were considered permissible⁷²². As organ donation activities steadily developed as a potential medical treatment for end-stage organ failure conditions, this progress also created an impact on the Muslim community all over the world as new issues started to arise for Muslim physicians, medical jurists and religious authorities⁷²³. Muslims started to ask whether they could also benefit from organ donation achievements, contribute as organ donors or become organ recipients themselves. Other issues raised included the types of organ donation approved, whether Islam allows both living and cadaver donations, and also the requirement for consent.

⁷¹⁷ Daar, A.S, 'The Response to the Challenge of Organ Shortage in the Middle East Region : A Summary' (1997) 29 *Transplantation Proceedings* 3215-3216

⁷¹⁸ Bruzzone, P, 'Religious Aspects of Organ Transplantation' (2008) 40 *Transplantation Proceedings*, 1064-1067. p.1064

⁷¹⁹ Seyyed Hossein Nasr. *Islamic Science An Illustrated Study* (England, World of Islam Festival Publishing Company Ltd, 1976) p.154

⁷²⁰ Rispler-Chaim, V, 'Islamic Medical Ethics in the 20th Century' (1989) 15 *Journal of Medical Ethics*, 203-208. p.203

⁷²¹ Al-Mousawi, M, Hamed T, and Al-Matouk, H, 'Views of Muslim Scholars on Organ Donation and Brain Death' (1997) 29 *Transplantation Proceedings*, 3217

⁷²² Rispler-Chaim, V, 'Islamic Medical Ethics in the 20th Century' (1989) 15 *Journal of Medical Ethics*, 203-208 p.204.

⁷²³ Vanzan Paladin A, 'Ethics and Neurology in the Islamic World. Continuity and Change' (1998) 19 *Ital J Neurol Sci* 255-258. p.255

The fact that organ donation is not mentioned directly in the primary sources of the *Shariah*⁷²⁴ has forced Muslim jurists to reach a consensus and decide on its permissibility. Consequently, this difference of opinion has resulted in some confusion among Muslims about the permissibility of having organ donation as an option for treatment of end-stage organ failure and has subsequently hindered further development of transplantation activities. All these factors generally contribute towards a more serious organ shortage problem.

For example, there are still Muslims that project Islam as the main obstacle to them taking part in organ transplantation, either by becoming organ donors or organ recipients. In a study conducted on 1,030 members of the public in the Turkish community, 26.2% claimed their refusal to become organ donors was due to religious belief⁷²⁵. A different study also conducted in Turkey revealed that religious people are very sensitive about organ donation matters and, overall, although a positive 84% were confident that organ donation was in accordance with the Islamic teachings, the remaining 16% still had doubts over its permissibility⁷²⁶.

Similarly, in Malaysia, through the researcher's study of the Malaysian public,⁷²⁷ it was discovered that the religious factor was not considered the main reason for Malaysians' reluctance to become organ donors, but a significant percentage of 13.3% still maintained that it was their main barrier. In a different survey conducted by the Islamic Understanding Foundation of Malaysia (IKIM) on 500 Malaysian Muslim respondents,

⁷²⁴ Primary sources of *Shariah* refers to the Al-Quran and Al-Sunnah.

⁷²⁵ Bilgel H, Bilgel N, Okan N, et al 'Public Attitudes towards Organ Donation: A Survey in a Turkish Community' (1991) 4 *Transplant Int.* 243-245.

⁷²⁶ Kecucioglu, N, Tuncer, M. Yucetin, L, Akaydin, M and Yakupoglu. G. 'Attitudes of Religious People in Turkey Regarding Organ Donation and Transplantation' (2000) 32 *Transplantation Proceedings*, 629-630 p.630

⁷²⁷ Results obtained from an empirical study relating to organ shortage problems in Malaysia conducted from December 2007 until February 2008, which was conducted in Klang Valleys, specifically in Kuala Lumpur and the district of Hulu Langat. Detailed results of the study are elaborated in chapter 4 of the thesis.

5.2% were unwilling to register as organ donors due to religious misconceptions⁷²⁸. Their hesitation was mainly based on the perception that they would later be resurrected as incomplete persons, the procurement procedure would hurt the deceased body and it would delay their burial ceremony⁷²⁹. These findings correlate with a different study on cadaveric organ donations at the University Hospital Malaysia where, again, it was proved that misinterpretation of religious teachings regarding organ transplantation is not the main reason for people's refusal to become organ donors, although it is still a contributing factor⁷³⁰.

In the United Kingdom, findings from a study which specifically examined the influence of religion on attitudes towards organ donation among the Asian population in Luton indicated that, within the population studied, culture and religion do play a much less prohibitive part in determining the level of organ donation than previously suggested⁷³¹. However, there is a great desire to raise awareness of these religious stances so that people are able to make a more informed decision⁷³². Again, the findings proved to be similar in principle as there is always a small portion which still believes Islamic teachings are stopping them from being involved in organ donation matters. So, steps must be taken to clear any existing doubts which prevent Muslims from benefiting from these organ donation achievements. Eliminating these confusions will hopefully enable more Muslims to contribute towards solving the organ shortage problem.

Islam is not only a religion but also a complete code of life⁷³³. It encompasses the secular and the spiritual, the mundane and the celestial through a holistic approach⁷³⁴. Islamic law aims to fulfil the interests of the people by securing for them the necessities of life and helping them to maintain their physical requirements and improve themselves. So,

⁷²⁸ Institute of Islamic Understanding Malaysia, (2006) *VISI*, Issue 61-Jan, p.18

⁷²⁹ *Ibid*

⁷³⁰ T.P.Chen, S.M.Teo, J.C.K.Tan, et al. 'Cadaveric Organ Donation at University Hospital Kuala Lumpur' (2000) 32 *Transplantation Proceedings* 1809-1810.

⁷³¹ Gurch Randhawa. 'An Exploratory Study Examining the Influence of Religion on Attitudes towards Organ Donation among the Asian Population in Luton, UK' (1998)13 *Nephrol Dial Transplant* .1949-1954.

⁷³² *Ibid.* p.1949

⁷³³ Abdel Moneim Hassaballah 'Definition of Death, Organ Donation and Interruption of Treatment in Islam' (1996) 11 *Nephrol Dial Transplant* 964-965.p.964

⁷³⁴ El-Shahat, Y. I. M. 'Islamic Viewpoint of Organ Transplantation' (1999) 31 *Transplantation Proceedings* 3271-3274 p. 3271.

matters which secure and maintain these lawful interests are considered lawful either to fulfil people's needs or simply to provide an easier and more comfortable life⁷³⁵. The core of Islamic teaching is the perfection of the ethical conduct of a human being⁷³⁶. Therefore, it is impossible to separate religious values from any discussions and decisions on new laws involving various aspects of life⁷³⁷. All social attitudes and ethical principles are closely intertwined with Islamic tradition, teachings and heritage, which are later generated into practice and are strongly adhered to, both in many Islamic countries and by Muslims living in countries that are not predominantly Islamic⁷³⁸.

Whenever Muslims are confronted with any new issue that needs to be resolved, the primary sources of Islamic law are first consulted for guidance and solutions. The first source of law is the *Quran* which is the holy text believed by Muslims to be the direct words of *Allah* (God). The second is the *Sunnah* which is the prophetic traditions of the Prophet Muhammad which includes his sayings, words, deeds and attributes. The third source, which is *Ijma*, refers to the general consensus among Islamic scholars of a particular age for the legal ruling applicable to the situation. For instance, if a consensus on a particular issue exists among the community of scholars in an area on which both the primary sources are silent, as long as it is consistent with the *Quran* and *Sunnah*, that view has validity⁷³⁹. However, in situations where none of the sources mentioned provides a ruling, the responsibility is consequently shifted to the jurists to try and derive an appropriate rule by logical inferences and analogy (*qiyas*), which is known as *ijtihad*⁷⁴⁰. By virtue of *ijtihad*, Islamic law continues to develop and remain relevant as it allows responses to be made to recent challenges and issues that have arisen within the

⁷³⁵ *Ibid*

⁷³⁶ Larijani, B. Zahedi, F. and Taheri, E, 'Ethical and Legal Aspects of Organ Transplantation in Iran' (2004) 36 *Transplantation Proceedings*, 1241-1244 p.1241

⁷³⁷ Abdel Moneim Hassaballah 'Definition of Death, Organ Donation and Interruption of Treatment in Islam' (1996) 11 *Nephrol Dial Transplant* 964-965 p.964

⁷³⁸ Seyed R. Mousavi Shahid Behesti, 'Ethical Considerations Related to Organ Transplantation and Islamic Law' (2006) 4 *International Journal of Surgery*, 91-93. p.91

⁷³⁹ Sahin Aksoy, 'A Critical Approach To The Current Understanding of Islamic Scholars on Using Cadaver Organs Without Prior Permission' (2001) *Bioethics*, Volume 15 Number 5/6 p.463

⁷⁴⁰ *Ibid*

Muslim culture through the process of continuous learning and scientific progress⁷⁴¹. Any decision-making must be carried out within a framework of values derived from revelation and tradition⁷⁴², which means that all solutions to ethical problems are derived from Islamic principles⁷⁴³.

The best way to legitimise a new, modern medical treatment for Muslims is to prove that a similar practice already exists in the Quran, can be traced from the Sunnah of Prophet Muhammad or is mentioned anywhere in the Islamic books⁷⁴⁴. In fact, both the Quran and Sunnah have laid down detailed and specific guidelines pertaining to various issues, including on medical matters. For example, the Quran contains a detailed description regarding the development of the embryo inside the womb⁷⁴⁵, which later stimulated further discussions on the ethical and legal status of the embryo and fetus after birth. However, there are also matters which are mentioned generally, without specifying the exact matter at issue, which includes rulings on organ transplantation matters. Organ transplantation is not discussed directly per se in the primary sources of Islamic Law; therefore, *ijtihad*, by using tools such as juristic consensus of opinion (*ijma*)⁷⁴⁶ or analogical deduction (*Qiyas*)⁷⁴⁷, must alternatively be resorted to⁷⁴⁸. Religious authorities and jurists will make analogies and inferences between the case in point and a similar one

⁷⁴¹ Gatrads, A.R. and Sheikh, A. 'Medical Ethics and Islam: Principles and Practice' (2001) 84 *Arch. Dis. Child.* 72-75, p.73.

⁷⁴² Abdallah S. Daar and A.Binsumeit Al Khitamy, 'Bioethics for Clinicians: 21. Islamic Bioethics' (2001) *Canadian Medical Association Journal*, 164(1): 60-63. p.60

⁷⁴³ Larijani, B, Zahedi, F, and Taheri, E 'Ethical and Legal Aspects of Organ Transplantation in Iran' (2004) 36 *Transplantation Proceedings*, 1241-1244. p.1241

⁷⁴⁴ Rispler-Chaim, V, 'Islamic Medical Ethics in the 20th Century' (1989) 15 *Journal of Medical Ethics*, 203-208, p.204

⁷⁴⁵ Al-Quran: *Surah Al-Sajdah*: 7-9. The translation of the verse is: "Who made all things good, which He created, and He began the creation of man from clay then He made his seed from a draught of despised fluid. Then He fashioned him and breathed into him His spirit, and He appointed for you hearing and sight and hearts. Small thanks do you give".

⁷⁴⁶ Muhammad Hashim Kamali in his book *Principles of Islamic Jurisprudence*, (1991) Cambridge, Cambridge Islamic Texts Society, p.169 defines *Ijma* as the unanimous agreement of the *mujtahideen* (jurists) of the Muslim community of any period following the demise of the Prophet Muhammad on any matter.

⁷⁴⁷ Muhammad Hashim Kamali in his book *Principles of Islamic Jurisprudence*, (1991) Cambridge, Cambridge Islamic Texts Society, p.169 defines *Qiyas* as the extension of a Shariah value from an original case to a new case because the latter has the same effective cause as the former.

⁷⁴⁸ Nazeem M.I.Goolam, 'Human Organ Transplantation-Multicultural Ethical Perspectives' (2002) 21 *MEDLAW* 541. p.544.

which is contained in the primary sources⁷⁴⁹. So, the Islamic Fundamental principles remain constant, but their application varies considerably⁷⁵⁰.

Whenever appropriate, consideration is also given to *maslahah*⁷⁵¹ (public interest) and *urf* (local customary precedent)⁷⁵². However all this must still be applied in the light of general guidance available in the primary sources. Islamic scholars will discuss the legal implications and parameters of each new incident to provide the most comprehensive legal judgement for each new issue put forward. By this approach, Islam has the flexibility to respond to new biomedical issues and technologies, especially with the emergence of complex ethical dilemmas faced by the medical community, patients and society at large. Most importantly, all decision-making must be carried out within a framework of values derived from these sources, as its interpretations will subsequently form the basis of Islamic law laid down. Often, the *ulamas* (Jurists)⁷⁵³ and scholars from Islamic universities, such as Al-Azhar in Cairo, are referred to for interpreting and contextualising religious teachings of the Quran and Sunnah for the wider Muslim community⁷⁵⁴. This decision-making process is transparent with members of the community being able to scrutinise the arguments put forward and all the textual material supporting their edicts. Counter-arguments may be presented and it is common for two or even more seemingly contrasting opinions to coexist⁷⁵⁵.

Since Islamic law is not monolithic, Muslims can be affiliated with different juridical schools and basically divided into Sunni and Shiites with both having their own school of

⁷⁴⁹ Vanzan Paladin, A, 'Ethics and Neurology in the Islamic World. Continuity and Change' (1998) 19 *Ital J Neurol Sci.* 255-258. p.258

⁷⁵⁰ *Ibid*

⁷⁵¹ *Maslaha*- The element of public benefit which is in line with the general spirit of Islamic Law and from which the public may benefit. It is considered permissible even though the primary sources do not mention anything about that particular issue. The *maslaha* is also one of the most useful tools of the Muslim jurists to fill legal lacunae, explanation from V. Rispler-Chaim, 'Islamic Medical Ethics in the 20th Century' (1989) 15 *Journal of Medical Ethics*, 203-208. p.204

⁷⁵² Muhammad Hashim Kamali. *Principles of Islamic Jurisprudence* (Cambridge, Cambridge Islamic Texts Society, 1991) p.283

⁷⁵³ Gatrad, A R ' Muslim Customs Surrounding Death, Bereavement, Postmortem examinations, and Organ Transplants' (1994) *BMJ* 309:521-523 (20 August) p.521

⁷⁵⁴ Gatrad, A R, and Sheikh, A, 'Medical Ethics and Islam: Principles and Practice' (2001) 84 *Arch. Dis. Child* 72-75, p.73.

⁷⁵⁵ *Ibid*

thought⁷⁵⁶. The Sunni school, for example, recognises four most important schools⁷⁵⁷ which differ in interpretation and legal formulation of the law. Subsequently, Muslims are free to choose whichever judgement they prefer and find most agreeable although, in practice, many will stick to their particular school of thought⁷⁵⁸. Consequently, there can be different views and various legal opinions on the same topic, although the overall principle referred to is the same⁷⁵⁹. To prove the flexibility of Islam in responding to new biomedical technologies⁷⁶⁰, many *ulamas* have required specialist knowledge from medical practice to provide them with a better, sounder understanding of the background of each issue concerned⁷⁶¹. Nevertheless, the general principle of Islamic Law in medical cases always emphasises preventions and instructs that all patients must be treated well, with compassion and respect. All aspects of the patient, including the physical, mental and spiritual dimensions of the illness experience, must be noted and taken into consideration⁷⁶².

As for organ transplantation matters in particular, guidance and fatwas on the subject were developed, during Islamic conferences on religious matters, which were not specifically mentioned in the Quran or the Sunnah⁷⁶³. It is worth noting that both the Quran and Sunnah neither sanction nor condemn its practice, thus providing room for Muslim jurists to attempt to deliver the answers in the light of the Islamic teachings available in the Quran and Sunnah⁷⁶⁴. Consequently, different viewpoints have resulted

⁷⁵⁶ Vanzan Paladin, A, 'Ethics and Neurology in the Islamic World. Continuity and Change' (1998) 19 *Ital J Neurol Sci* 255-258. p.256

⁷⁵⁷ The four schools of law are the Hanafi, Shafie, Maliki and Hambali. Their legal activities crystallized around the eighth and ninth centuries.

⁷⁵⁸ Gatrad, A R, and Sheikh, A, 'Medical Ethics and Islam: Principles and Practice' (2001) 84 *Arch. Dis. Child.* 72-75. p.73.

⁷⁵⁹ Vanzan Paladin, A, 'Ethics and Neurology in the Islamic World. Continuity and Change' (1998) 19 *Ital J Neurol Sci* 255-258. p.256

⁷⁶⁰ Abdallah S.Daar, A.Binsumeit Al Khitamy, 'Bioethics for Clinicians: 21.Islamic Bioethics' (2001) *Canadian Medical Association Journal*, 164(1) 60-63

⁷⁶¹ Gatrad, A R, and Sheikh, A, 'Medical Ethics and Islam: Principles and Practice' (2001) 84 *Arch. Dis. Child.* 72-75. p.73.

⁷⁶² *Ibid.*

⁷⁶³ A *Fatwa* is a formal legal opinion or interpretation given by Jurisconsult (*mufti*) or leading Muslim scholars or the consensus of learned opinions in response to a request from a judge (*Qadhi*) or governmental authorities or ordinary people on certain current issues raised. This legal opinion is often expressed in a question-answer format.

⁷⁶⁴ Abul Fadl Mohsin Ebrahim, 'Organ Transplantation: Contemporary Sunni Muslim Legal and Ethical Perspectives' (1995) *Bioethics* Volume 9, 291-302. p.292

on the same issue, which explains the doubts and dilemmas faced by practising Muslims⁷⁶⁵. For instance, the Islamic Code of Medical Ethics in 1981 approved the practice of organ donation⁷⁶⁶ although, initially, there was some resistance, based on cultural reasons rather than religious reasons, to accepting it into the Islamic world⁷⁶⁷. The Muslim jurists involved had discussed the matter in detail and adopted a unanimous consensus based on the principle of “the needs of a living human being have priority over those of a dead one”; thus, organ donation was accepted⁷⁶⁸.

This change was a very important decision that led to changes in attitudes towards the deceased body. By virtue of this Islamic Code, physicians were also given the responsibility to find the needed organs, verify the donor’s death and practically conduct the transplantation procedures⁷⁶⁹. However, the doctors involved in verifying the donor’s death should not be those involved in the transplant surgery; this is to avoid possible premature advice to extract organs from terminally ill patients, favouring the other party⁷⁷⁰. Additionally, no restriction on organ donation between different religions in normal circumstances was clearly decided upon⁷⁷¹.

7.2 ARGUMENTS SUPPORTING ORGAN DONATION

Islam respects the human being both during life and after death. Thus, any matters related to these issues are treated with sensitivity and priority. Muslims are expected to be moderate and balanced in all matters including their health. This is mainly because all humans are treated as the crown of creation and are God’s vicegerents on earth⁷⁷².

⁷⁶⁵ *Ibid*

⁷⁶⁶ *World Med.J.* (1982) 29 (5) 78-80.

⁷⁶⁷ Abdel Moneim Hassaballah, ‘Definition of Death, Organ Donation and Interruption of Treatment in Islam’ (1996) 11 *Nephrol Dial Transplant* 964-965. p.964

⁷⁶⁸ Vanzan Paladin, A, ‘Ethics and Neurology in the Islamic World. Continuity and Change’ (1998) 19 *Ital J Neurol Sci* 255-258. p.257

⁷⁶⁹ International Organization of Islamic Medicine (1981) *Islamic Code of Medical Ethics*. Kuwait City. p.81.

⁷⁷⁰ Vanzan Paladin, A, ‘Ethics and Neurology in the Islamic World. Continuity and Change’ (1998) 19 *Ital J Neurol Sci*. 255-258. p.258

⁷⁷¹ Seyed R. Mousavi Shahid Behesti, ‘Ethical Considerations Related to Organ Transplantation and Islamic Law’ (2006) 4 *International Journal of Surgery*, 91-93. p.92

⁷⁷² Al- Quran: Surah Al-Baqarah:30

a) PRESERVATION OF LIFE

Islam also puts priority on the preservation of life in all situations, as termination of the life of a person is equivalent to the termination of the life of all humanity; conversely, the saving of one life is regarded as the saving of all humanity. This is based on the following Quranic verse:

*“...whoever kills a human being for other than killing or corruption in the earth, it shall be as if he had killed all mankind and who ever saves the life of one, it shall be as if he had saved the life of all mankind”*⁷⁷³

This verse clearly signifies how human life is valuable and must be protected and preserved. The maintenance of human life is one of the ultimate goals of Islamic legislation besides protection of individual freedom of belief, intellect, honour and integrity, and property⁷⁷⁴. This requires that all possible means should be used for treating and saving human life, provided that they are legally acceptable. Thus, taking into consideration the verse above, organ donation procedures carried out with the aim of saving lives would, without doubt, be considered an effort to preserve precious human life while making legitimate any form of medical advances which save human lives⁷⁷⁵. This means that organ donation is strongly encouraged in Islam provided that it does not significantly harm the donor, for example, by causing death or any permanent disability⁷⁷⁶. Reflecting back on Islamic history, during the days of Badar and Uhud war, it was reported that Prophet Muhammad had even replanted the eye of Qatada Ibn Nukman, which had nearly come out, and had reconnected the hands of Muawith Ibn Afra and Habib Ibn Yusuf⁷⁷⁷. Later, there were also other incidents where Islamic medical doctors had transplanted bones from humans and animals into injured soldiers during war⁷⁷⁸. All of this provides strong evidence that organ donation is permissible and approved by the teachings of Islam.

⁷⁷³ Al-Quran: Surah Al-Maidah:32

⁷⁷⁴ Gatrad A R, and Sheikh A, ‘Medical Ethics and Islam: Principles and Practice’. (2001) 84 *Arch. Dis. Child.* 72-75. p.73.

⁷⁷⁵ Abdel Moneim Hassaballah, ‘Definition of Death, Organ Donation and Interruption of Treatment in Islam’ (1996) 11 *Nephrol Dial Transplant* 964-965.p. 964

⁷⁷⁶ Al-Mousawi, M, Hamed T, and Al-Matouk, H , ‘Views of Muslim Scholars on Organ Donation and Brain Death’ (1997) 29 *Transplantation Proceedings* 3217

⁷⁷⁷ Abu Bakar Yang, ‘Sejarah Pemindahan Organ dan Tisu’, (2006) *VISI*, Issue 61-Jan, Institute of Islamic Understanding, Malaysia.

⁷⁷⁸ *Ibid*

Although all the religious leaders agree that human beings do not own their bodies, as they actually belong to *Allah* (God), the majority view convincingly still permits and positively responds to organ donation done with the intention of saving lives and curing serious diseases⁷⁷⁹. Saving the life of a living person is more important than the sacredness of the deceased person because the end justifies the means⁷⁸⁰. Some may argue that it violates the cadaver⁷⁸¹, but this contention is refuted by the argument that one is permitted to commit a lesser evil in order to combat a greater evil; in other words, if the general gain outweighs the negative aspect of an action, it is allowed, but if the negative consequences of such action outweigh the good, then it is prohibited⁷⁸². So, permitting organ transplantation is weighed as a lesser evil than allowing the death of a patient to take place if the transplantation cannot occur. Analogically, Islamic Law does allow the belly of a dead pregnant woman to be cut for the sake of removing the foetus if there are any signs of life detected from the foetus⁷⁸³. However, it is undeniable that Islam forbids any act of aggression against human life as well as the body after death, but reliance on the doctrine of *Maslahah Mursalah*⁷⁸⁴ makes the public interest and benefit outweigh the negative aspect of such action. This means that, while the deceased body needs to be respected, the life of a living human is considered to be more valuable and should be saved when the two are in conflict.

It is equally important to honour the sacredness of the body and it is an important interest that must be respected; however, maintaining the health of the members of the nation as much as possible and protecting them from suffering and death is even more essential. Allah said the following to this effect:

⁷⁷⁹ Al-Mousawi, M, Hamed T, and Al-Matouk, H , ‘Views of Muslim Scholars on Organ Donation and Brain Death’ (1997) 29 *Transplantation Proceedings* 3217

⁷⁸⁰ El-Shahat, Y. I. M, ‘Islamic Viewpoint of Organ Transplantation’ (1999) 31 *Transplantation Proceedings*, 3271-3274 .p. 3273

⁷⁸¹ Nazeem M.I.Goolam, ‘Human Organ Transplantation-Multicultural Ethical Perspectives’ (2002) 21 *MEDLAW* 541. p.544.

⁷⁸² Abul Fadh Mohsin Ebrahim, ‘Organ Transplantation: Contemporary Sunni Muslim Legal and Ethical Perspectives’ (1995) *Bioethics*, Volume 9 Number 3/4 291-302, p.295

⁷⁸³ *Ibid*

⁷⁸⁴ Refer footnote 34 for definition of *Maslaha*

*“He had explained to you in detail what is forbidden to you, except under compulsion or necessity”*⁷⁸⁵.

Islam emphasizes that it is crucial and significant to save and maintain human life. That is why, in certain situations of “*dharurah*” (necessity), an exception can be made to allow and make permissible things that are forbidden in normal circumstances. Muslims are allowed to do what is forbidden if they are exposed to danger or imminent death⁷⁸⁶. For example, the prohibition on Muslims eating carrion or drinking wine is suspended in situations of extreme necessity so as to maintain survival and life. This is illustrated by a verse in the Quran which says the following:

*“He has forbidden you only carrion and blood and swine flesh, and that which has been sanctified to (the name of) any other than Allah. But he who is driven by necessity, neither craving nor transgressing, it is no sin for him. Allah is Forgiving, Merciful”*⁷⁸⁷

b) NECESSITY MAKES FORBIDDEN THINGS PERMISSIBLE

Necessity or great need can be relieved by using prohibited matters, which eventually puts aside the evil and gives priority to the resulting benefit⁷⁸⁸. There is a juristic legal maxim that says, “Necessity makes forbidden things permissible”⁷⁸⁹. This again stresses that whatever is legally forbidden becomes permissible in circumstances of extreme necessity. People’s need of life-saving treatment and efforts taken to eliminate the danger of organ diseases by having organ transplantation is considered a necessity which justifies the means⁷⁹⁰. A ‘need’ may be considered an extreme necessity whether it be for an individual or in general, particularly when it persists and represents danger⁷⁹¹. So, if a

⁷⁸⁵ Al- Quran. Surah Al-Nahl: 89.

⁷⁸⁶ El-Shahat, Y. I. M, ‘Islamic Viewpoint of Organ Transplantation’ (1999) 31 *Transplantation Proceedings*, 3271-3274, p. 3273

⁷⁸⁷ Al-Quran. Surah Al-Baqarah : 173.

⁷⁸⁸ Shaheen, F.A.M., and Souqiyyeh, M.Z, ‘Increasing Organ Donation Rates From Muslim Donors : Lessons From A Successful Model’ (2004) 36 *Transplantation Proceedings* 1878-1880, p.1879

⁷⁸⁹ Ibn Nujaym, al-Ashbah wa al-Naza’ir, p.85

⁷⁹⁰ Y. I. M. El-Shahat, ‘Islamic Viewpoint of Organ Transplantation’ (1999) 31 *Transplantation Proceedings*, 3271-3274, p. 3273

⁷⁹¹ *Ibid*

skilled and reliable doctor decides that, in the best interests of the patient and to save his/her life, there is a need to take an organ from a donor and transplant it into the patient, that practice will be considered to be in harmony with the teachings of Islam as it is done in due course of necessity. The Supreme Council of Ulama in Riyadh has allowed both organ donation and organ transplantation in the case of necessity⁷⁹². This was followed by another confirmation of acceptance of organ donation and transplantation activities by the Fiqh Academy of the Muslim World League in Makkah, in its 8th Session⁷⁹³.

c) HELPING EACH OTHER BASED ON BROTHERHOOD

It is evident that organ transplantation is a life-saving treatment; thus, the general rules on life-saving treatments are applicable to organ transplantation procedures⁷⁹⁴. Furthermore, Islam also encourages its believers to help each other as they are considered brothers. The Quran states to the effect,

*“Help you one another in righteousness and piety”*⁷⁹⁵

The verse clearly urges Muslims to strengthen their religious ties through brotherly love and mercy, so that they may be like one unified body. By having organ donation, clearly this spirit of helping each other, cooperation and gifting is encouraged. This also closely relates to the concept of *Maslahah Mursalah* where priority consideration is given to the public interest and the general welfare of the community at large over specific individuals⁷⁹⁶.

⁷⁹² Resolution No. 99 dated 6 Dzul Qi'dah 1402 quoted in Medical Fatawa dated 22 May 2006. *Organ Donation*. World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/>. Viewed on 4 February 2009.

⁷⁹³ The Session was held between 28 Rabi'ul Thani-7 Jumadul Ula, 1405. Quoted in Medical Fatawa dated 22 May 2006. *Organ Donation*. World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/>. viewed on 4 February 2009.

⁷⁹⁴ Sahin Aksoy, 'A Critical Approach To The Current Understanding of Islamic Scholars on Using Cadaver Organs Without Prior Permission' (2001) *Bioethics*, Volume 15 Number 5/6 p.466

⁷⁹⁵ Al-Quran. Surah Al-Maidah:2

⁷⁹⁶ Nazeem M.I.Goolam, 'Human Organ Transplantation-Multicultural Ethical Perspectives. 21' (2002) *MEDLAW* 541. p.544.

d) SEEKING CURE AND TREATMENT FOR ILLNESS

Although Muslims understand that illnesses, sufferings and dying are part of life and represent a test from Allah⁷⁹⁷, Islam also enjoins its believers to seek remedies. In a renowned saying, the Prophet Muhammad is reported to have said, “*There is a cure for every illness, though we may not know it yet*”⁷⁹⁸.

In another Sunnah, The Prophet also said,

“*O servants of Allah! Seek remedies! He who causes ailments also brought cures and redemption. There is a cure for every illness*”⁷⁹⁹.

Seeking treatment is specifically urged by Islam for hereditary as well as acquired diseases and ailments. This in no way conflicts with the Islamic teachings of perseverance and acceptance of God’s will⁸⁰⁰. The sick patient who shows fortitude and acceptance of his sufferings will gain Allah’s credit⁸⁰¹ as Islam enjoins its people to protect the security, health and safety of Muslims and considers lawful any effort to treat and cure diseases.

Illness may be seen as a trial or a means to cleanse an ordeal, but it is not viewed as a curse or punishment or even an expression of Allah’s wrath. That is why patients have the obligation to seek treatment and avoid being fatalistic, while physicians have the responsibility to strive to cure and heal the patient, although Allah is indeed the ultimate healer⁸⁰². This justifies new methods of treatment including organ donation which should be accepted as it will result in great benefit and has proved successful in saving many patients’ lives. This also extends the discussion on how Islam promotes the perseverance

⁷⁹⁷ G.Hussein Rassool, ‘The Crescent and Islam: Healing, Nursing and Spiritual Dimension. Some Considerations towards an Understanding of the Islamic Perspectives on Caring’ (2000) 32(6) *Journal of Advanced Nursing*, 1476-1484, p.1479

⁷⁹⁸ Al-Bukhari MI, *Sahih al Bukhar*, 1958 Vol.7. Cairo. Maktabat al-Shcab. (Kitab al-Tib)

⁷⁹⁹ Al-Bukhari MI: *Sahih Al-Bukhar*, 1958 vol.2. Cairo: Matbaat Al-Sihaba, p.107.

⁸⁰⁰ Muzammil Siddiqi. Organ Donation. <http://www.oxfordislamstudies.com/article/book/islam-9780195174304/islam-9780195174304-chapter->

⁸⁰¹ Abdel Moneim Hassaballah, ‘Definition of Death, Organ Donation and Interruption of Treatment in Islam’ (1996) 11 *Nephrol Dial Transplant* 964-965, p.965.

⁸⁰² Abdallah S.Daar and A. Binsumeit Al Khitamy, ‘Bioethics for Clinicians: 21 Islamic Bioethics’ (2001) *Canadian Medical Association Journal*, 164(1) 60-63, p.60

of human life, again highlighting how organ donation makes this possible. Any harm done by removing an organ from a deceased individual should be weighed against the benefit obtained and the new life restored to the recipient. Thus, the principle of saving human life takes precedence over whatever assumed harm might occur to the deceased body.

e) ENJOINING ALTRUISM

Another value that is strongly promoted in Islam is altruism, where one puts the interest of one's fellow Muslims above one's own. This is indeed considered an exceptional ideal because one must undergo hardship for the sake of assisting one's brother. So, in relation to organ donation issues, this spirit is conceptualized when a person is willing to donate their organs after death in order to save the lives of their brothers who are in need of the organs to survive. This benevolent deed is based solely on altruism as Muslims believe that human beings are equal and there is a moral obligation to help others by saving lives⁸⁰³. Allah says the following:

“Help you one another in righteousness and piety”⁸⁰⁴. This spirit of helping each other is also emphasized by the Prophet when he said,

*“Whoever helps a brother through his difficulty, God will help him through his difficulties on the Day of Judgement”*⁸⁰⁵.

The Prophet also said, *“The believers, in their love and sympathy for one another, are like a whole body; when one part of it is affected with pain the whole of it responds in terms of wakefulness and fever”*⁸⁰⁶.

Moreover, organ donation is also considered a charitable contribution which is highly recommended in Islam. Muslims are rewarded by Allah if they contribute “*Sadaqat ul Jarriyya*” (charity contributions) to others. In the Quran, Allah mentions,

⁸⁰³ Orit Brawer Ben-David and Aref Abu-Rabia, ‘The Experiences of Islamic Minorities in Non-Islamic States’ (2002) 21 *MEDLAW* 281, p.5

⁸⁰⁴ Al-Quran. Surah Al Maidah : 2

⁸⁰⁵ Hadith cited from ‘The Muslim Law (Shariah) Council and Organ Transplants’, (1996) 4 *Accident and Emergency Nursing*, 73-75, p.74.

⁸⁰⁶ Sahih al Bukhari, Kitab al Adab. Part 8, p.12

“Allah has forbidden you not those who warned not against you on account of religion and drove you not out from your homes, that you should show them kindness and deal justly with them. Allah loves the just dealers”⁸⁰⁷.

Therefore, being generous and bestowing favours is required⁸⁰⁸. A contemporary Muslim scholar, Dr.Yusuf Qardawi, during the First GCC Organ Transplantation Congress in Abu-Dhabi, in February 1998, stated in his fatwa that:

“The attitude of Islam regarding organ donation and organ transplantation is clear and unquestionable. On different occasions we informed the medical organisations in all Arabic and Islamic countries of the legal Islamic opinion which is in favour of organ donation, as long as we are sure that all the moral and religious conditions have been met”. This shows that Islam is in favour of organ donation; however it must only be practised within certain religious restrictions. For example, organ donation must only be carried out as a means of treatment and if there is a high degree of success resulting from it⁸⁰⁹. Elements of consent must also be obtained from the donor him/herself or at least his/her heirs⁸¹⁰. The organ can be taken from the body of a living person with his/her consent, but the jurists have stipulated that this kind of donation must not deprive him/her of his/her vital organs or cause risks to his/her normal life⁸¹¹. As for cadaver donations, death must be fully established and the recipient patient also needs to be informed so that he/she really understands the intended operation and its possible implications⁸¹².

Islamic jurisprudence does not prevent Muslims from donating to non-Muslims or vice versa. According to Dr.Yusuf Qardawi, body parts of human beings cannot be considered to have become believers or non-believers in Islam. Rather, all body parts are to be

⁸⁰⁷ Al-Quran., Surah Al-Mumtahinah : 8

⁸⁰⁸ Quoted from Orit Brawer Ben-David and Aref Abu-Rabia, ‘The Experiences of Islamic Minorities in Non-Islamic States’ (2002) 21 *MEDLAW* 281. p.287

⁸⁰⁹ Abul Fadl Mohsin Ebrahim, ‘Organ Transplantation: Contemporary Sunni Muslim Legal and Ethical Perspectives’ (1995) *Bioethics*, Volume 9, 291-302. p.296

⁸¹⁰ *Ibid.* p.292

⁸¹¹ Muzammil Siddiqi, Medical Fatawa dated 22 May 2006. *Organ Donation*. World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/>. viewed on 4 February 2009.

⁸¹² Abul Fadl Mohsin Ebrahim, ‘Organ Transplantation: Contemporary Sunni Muslim Legal and Ethical Perspectives’ (1995) *Bioethics*, Volume 9, 291-302. p.296

considered as believers in Islam already, since everything that is contained in the human body praises the Lord. So, accordingly, it is permissible for a Muslim to receive a bodily organ from a non-Muslim and, in the same way, a Muslim is allowed to give a bodily organ to a non-Muslim. But, of course, priority is given to a Muslim in cases where a donating Muslim is offered a choice⁸¹³. Dr.Yusuf Qardawi added that it is not permissible to donate an organ to a non-Muslim combatant who wages war against Muslims or a person who perpetrates attacks on Islam. Additionally, it is not permissible to donate organs to an apostate as he/she is no less than a traitor to his/her religion and people⁸¹⁴. In cases where there is both a Muslim and a non-Muslim in need of the organ or blood donation, the Muslim must be given priority. This is based on the Quranic verse which states to the effect,

*“The believers, men and women, are protectors of one another”*⁸¹⁵.

It is also of significance to note that a Muslim can donate his/her organs to a certain person, or to an established institution such as a bank specified for that purpose⁸¹⁶.

Finally, there are strong arguments put forward to support organ transplantation which basically rely on the concept of necessity, promoting a lesser evil and comparing the most benefit that would result from the conflicting interests. Based on the principles and arguments put forward, Muslims are permitted to donate organs both during life and after death. There is also no restriction on the distribution and allocation of organs harvested. In line with the spirit of brotherhood, mercy and compassion it promotes towards all inhabitants in this world, Islam allows Muslims to donate organs to Muslims and non-Muslims alike. This indirectly reflects that Islam is not a religion that promotes discrimination among its believers, certainly not in a situation of necessity where precious human lives are at stake.

⁸¹³ Medical Fatawa dated 29 June 2007. *Donating Organs to Non-Muslims*. World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/>, Viewed on 4th February 2009.

⁸¹⁴ *Ibid*

⁸¹⁵ Al-Quran. Surah Al-Tawbah : 71.

⁸¹⁶ Medical Fatawa dated 29 June 2007. *Donating Organs to Non-Muslims*. World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/>. Viewed on 4 February 2009.

7.3 ARGUMENTS AGAINST ORGAN DONATION

Despite strong arguments in favour of organ donation, there is still another view that argues that it is not permissible for Muslims.

a) THE HUMAN BODY IS A DIVINE TRUST

These Islamic scholars contend that the human body is the sole property of *Allah*. The donor of life is *Allah* and the determinant of death is also *Allah*. So, because a person does not own his/her body, the individual cannot therefore decide to give away any parts of his/her body to another person. No man or authority has the right to decide fate or end a human's life⁸¹⁷, any more than to give away their body parts to others. The human body is sacred and regarded as an "*amanah*" (divine trusteeship)⁸¹⁸ given by *Allah*, the Creator. *Allah* is the sole owner of the Trust while the human being is God's trustee. Similarly to the concepts in the Law of Trust, a trustee must act in accordance with the wishes of the owner of the Trust. From this point of view, donation of human organs would not be permissible as one cannot conduct conveyance of something of which one is not the true owner⁸¹⁹. A comparison was also made between organ donation and the prohibition of selling organs. The latter is prohibited according to the Islamic Law as it is considered that one is not allowed to sell something that one does not really own. Let us apply this reasoning to organ donation cases in particular: as we do not own our organs, it is impossible for us to decide to donate them to someone else⁸²⁰. The body of a person either living or dead actually belongs to *Allah* alone. Therefore, no-one, not even his/her descendants, has any right to sell, donate or even dispose of his/her body except to bury him/her according to the principles of Islam⁸²¹.

⁸¹⁷ Abdel Moneim Hassaballah, 'Definition of Death, Organ Donation and Interruption of Treatment in Islam' (1996) 11 *Nephrol Dial Transplant*, 964-965, p. 964

⁸¹⁸ Abul Fadl Mohsin Ebrahim, 'Organ Transplantation: Contemporary Sunni Muslim Legal and Ethical Perspectives' (1995) *Bioethics*, Volume 9, 291-302, p.292

⁸¹⁹ Nazeem M.I.Goolam, 'Human Organ Transplantation-Multicultural Ethical Perspectives. 21' (2002) *MEDLAW* 541, p.544.

⁸²⁰ Abul Fadl Mohsin Ebrahim, 'Organ Transplantation: Contemporary Sunni Muslim Legal and Ethical Perspectives' (1995) *Bioethics*, Volume 9, 291-302, p.293

⁸²¹ *Ibid.* p.294

b) PROTECTING THE SANCTITY OF THE DEAD

Not only is the individual forbidden to dispose of his/her own body by damaging it through amputation or extreme punishment, but mutilation and suicide are also forbidden. Verses in the Al-Quran say to the effect,

*“Do not kill (or destroy) yourselves: verily Allah has been to you Most Merciful”*⁸²².

and

*“Make not your hands contribute to your own destruction”*⁸²³.

These two verses clearly explain that one cannot kill or destroy oneself, nor is one allowed to abuse the sanctity of another individual, cause assault or inflict injury on him, as these practices are not permissible in Islam. However, there are certain exceptions granted to the court of law, which may accordingly pass a death sentence against a person as punishments for crimes committed, for example, following conviction for premeditated murder or any other serious crimes⁸²⁴. The Quran also warns man about the consequences of taking someone’s life, as based on this verse where Allah says that,

*“If anyone slays a human being unless it be (in punishment) for murder or for spreading corruption on earth, it shall be as if he has slain the whole of mankind; whereas if anyone saves a life, it shall be as if he had saved the life of all mankind”*⁸²⁵.

After consideration of all the verses discussed above, some Muslim jurists have concluded that, since Islam forbids any act of aggression against human life as well as the body after death, organ donation from cadavers is an act equal to mutilating the corpse and, thus, should not be permissible. The Prophet Muhammad is reported to have stated, *“Breaking the bone of the dead person is similar in sinfulness and aggression to breaking it while the person is alive”*⁸²⁶.

This Sunnah supports the argument put forward that Islam stresses the importance of body wholeness at death⁸²⁷ and is against any form of bodily aggression which could lead to mutilation of the body⁸²⁸.

⁸²² Al- Quran. Surah Al-Nisa’: 29.

⁸²³ Al-Quran, Surah Al Baqarah:295

⁸²⁴ Medical Fatwa dated 26 June 2007. ‘Is Euthanasia Allowed in Islam? World Management and Research Institute Islamic Science University of Malaysia, <http://infad.usim.edu.my/viewed> on 4 February 2009.

⁸²⁵ Al-Quran: Surah Al Maidah: 35.

⁸²⁶ Sunan Abi Da’ud, Hadith no. 3207, Vol.2, pp.212-213.

⁸²⁷ Courtney S. Campbell, ‘Religion and the Body in Medical Research’ (1998) 8.3 *Kennedy Institute of Ethics Journal* 275-305, p.276

Another substantial argument put forward states that, if organ donation were allowed, it would delay the burial and possibly violate the integrity of the deceased body⁸²⁹. The teachings of Islam encourage the burial of the dead corpse as an intact cadaver as soon as possible, out of respect for bodily sanctity⁸³⁰. Muslim corpses are not cremated⁸³¹. However, when organ donation procedures are to take place from cadaver donors, this will obviously cause some significant delay in the burial process. Corpses of the dead must also be treated with respect and Islam strongly prohibits mutilation or any destruction of the body. However, this sanctity can only be broken if it conflicts with a more important and urgent interest, for example, for the sake of saving another human being's life⁸³². So, in conclusion, it seems that arguments against organ transplantation are primarily based on two main factors, which relate to treating the human body as a divine trust and protecting the sanctity of the dead.

7.4 ISLAM AND LIVING DONATION

Generally, organ donations from living donors are permissible in Islam. However, the principle of “doing no harm” takes priority in the application of the procedure. Donors are not allowed to give up one of their vital organs before death⁸³³, which would then cause danger and subsequently end their life. For example, donating one's heart to another person while one is still alive is not allowed as this would surely cause death to the donor: no-one can survive without a heart, which is needed to pump oxygen and blood to the body. Consequently, this would be regarded as an act of homicide or suicide, which is considered the most abominable of crimes in Islam. Basically, every donation should cause no harm or, at the very most, only a minimal increased risk to the health of

⁸²⁸ Abul Fadl Mohsin Ebrahim, ‘Organ Transplantation: Contemporary Sunni Muslim Legal and Ethical Perspectives’ (1995) *Bioethics*, Volume 9, Number 3/4, 291-302, p.293

⁸²⁹ Umit S. Sehirli, Erdinc Saka and Ozlem Sarikaya, ‘Attitudes of Turkish Anatomists toward Cadaver Donation’ (2004) 17 *Clinical Anatomy* 677-681, p.680.

⁸³⁰ Courtney S. Campbell, ‘Religion and the Body in Medical Research’ (1998) 8.3 *Kennedy Institute of Ethics Journal*, 275-305, p.293

⁸³¹ Black J, ‘Broaden Your Mind About Death and Bereavement in Certain Ethnic Groups in Britain (1987) *BMJ* 295:538

⁸³² M.Al-Mousawi, T.Hamed and H.Al-Matouk, ‘Views of Muslim Scholars on Organ Donation and Brain Death’ (1997) 29 *Transplantation Proceedings*, 3217

⁸³³ Larijani, B. Zahedi, F. and Taheri, E, ‘Ethical and Legal Aspects of Organ Transplantation in Iran’ (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1241

the donor. This also re-emphasizes the principle that life is sacred; thus, it is considered of great importance to be well-maintained and protected.

Generally, most Islamic scholars *do* permit all types of organ donation once certain requirements are fulfilled. In living donations, consent must be obtained from both donor and recipient⁸³⁴. The Senior Ulama Commission's Decision in 1982 stated: "The board unanimously resolved the permissibility of removing an organ, or a part thereof from a Muslim or a non-Muslim living person and grafting it into someone else should the need arise, as long as the following two conditions are met:

- 1) that there be no exaggerated anticipated risk to the donor in the removal; and
- 2) the transplantation seems likely to be successful"⁸³⁵.

Later, in June 1988, Dr. Sheikh Muhammed Tantawi, the Grand Mufti of Egypt, in his Fatwa also allowed living organ donations provided that they are done with adherence towards religious and judicial conditions. Another similar fatwa further supporting living organ donation is from the Al-Azhar University in Cairo dated 4th January 1994, which states,

"It is allowed for a person to donate an organ while he is alive, as long as this does not unduly endanger his life and it follows the religious and legal conditions"⁸³⁶.

So, from all the above, it can be concluded that organ donation from living donors is allowed as long as the element of consent exists and it does not cause substantial harm to the living donor. Sheikh Ahmad Kutty, an Islamic scholar at the Institute of Toronto, Ontario, Canada, concurs with those previous views, but added that the required consent must be obtained from a person who is in full possession of his/her faculties and is able to make a sound decision for him/herself. He/she must be an adult of at least twenty-one years old, and the donation must be done of his/her own free will without any external pressure being exerted upon him/her. He also emphasized that the donation must not be a

⁸³⁴ Larijani, B. Zahedi, F. and Taheri, E, 'Ethical and Legal Aspects of Organ Transplantation in Iran' (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1241

⁸³⁵ Purport of the Senior Ulama Commission's Decision, No.99, dated 6/11/1402 H. (1982 A.C.E.)

⁸³⁶ El-Shahat, Y. I. M. 'Islamic Viewpoint of Organ Transplantation' (1999) 31 *Transplantation Proceedings*, 3271-3274, p. 3271

vital organ upon which he/she is depending for survival and sound health⁸³⁷. Transplantation of sexual organs, however, is not permissible⁸³⁸.

Living organ donations are normally categorised into related and unrelated organ donations. Basically, the Islamic jurists have agreed that both types are permissible as long as the main element of consent is in existence. It is also permissible for the organ recipient to show gratitude towards the organ donor by offering a gift, such as money⁸³⁹. Nevertheless, this must not be regarded as payment for the organs since organ-selling is not permitted by most religious scholars⁸⁴⁰.

In a separate study conducted among thirty-two senior scholars from six Islamic countries of Kuwait, Saudi Arabia, Iran, Egypt, Lebanon and Oman, twenty-one scholars agreed that the donor should be permitted to ask the donee for a reward in return for his donated organ⁸⁴¹. However, this does not affect the principle that human organs are not ordinary property or commodities, which means that they should be donated freely in response to altruistic feelings of brotherhood and love for one's fellow beings⁸⁴². Donations of organs must not be considered a legitimate way of trading or even a means of earning a regular living⁸⁴³.

There is also a view that suggests the possibility for some financial transaction to be acceptable based on the fact that Islam is robust and a natural way of life⁸⁴⁴. Ibn Qudama, in the 14th Century, had allowed the sale of an organ of a living person which later

⁸³⁷ Medical Fatawa dated 16 June 2006. *Islam's View on Organ Transplants and Donations*. World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/viewed> on 4 February 2009.

⁸³⁸ *Ibid*

⁸³⁹ Larijani, B. Zahedi, F. and Taheri, E ' Ethical and Legal Aspects of Organ Transplantation in Iran' (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1243

⁸⁴⁰ *Ibid*

⁸⁴¹ Al-Mousawi, M, Hamed ,T and Al-Matouk, H, 'Views of Muslim Scholars on Organ Donation and Brain Death' (1997) 29 *Transplantation Proceedings*, 3217

⁸⁴² Sahin Aksoy, ' A Critical Approach to The Current Understanding of Islamic Scholars on Using Cadaver Organs Without Prior Permission' (2001) *Bioethics*, Volume 15, Number 5/6, p.468

⁸⁴³ *Ibid*

⁸⁴⁴ *Ibid*

become the basis for further allowing organs from deceased persons to be re-used⁸⁴⁵. According to Al-Mahdi, Chairman of the Neurosurgery Department at Ibn Sina Hospital in Kuwait, we must countenance the possibility of offering the donors some “material recompense”, especially during times when organs are very scarce and the supply is inadequate⁸⁴⁶. He also suggested that the amount for “material recompense” should be half the blood money, which is also equivalent to the sum of money paid by the Health Ministry to obtain a kidney from abroad⁸⁴⁷. This view is supported by Sheikh Muhammad Tantawi, the Grand Mufti of Egypt, who, although he was generally against organ trading and considered such transactions invalid and prohibited, nevertheless made an exception for it, especially in very rare cases where reliable doctors decided that a patient’s life was totally reliant upon that sale¹. So, to conclude, although the majority agree that there should be no monetary transactions or any financial benefit involved from the organ donation, the ruling is not absolute and can be waived depending on the urgency of each case although this, perhaps, is very unlikely to happen.

7.5 ISLAM AND CADAVERIC DONATIONS

Organ donation from cadaver donors has been accepted and approved by the majority of Muslim scholars. The Senior Ulama Commission’s Decision in 1982 resolved, by majority vote, that it is permissible to remove an organ or part thereof from a dead person for the benefit of another Muslim, taking into consideration the necessity of doing so and the likelihood of its success⁸⁴⁸. Later, Dr. Sheikh Muhammed Tantawi, the Grand Mufti of Egypt, in his Fatwa of June 1988, also permitted cadaver organ donations carried out with the intention of saving another person’s life or helping him/her recover from illness⁸⁴⁹. Another well-known contemporary Muslim scholar, Dr. Yusuf Qaradawi, during the First GCC Organ Transplantation Congress in Abu-Dhabi, in February 1998, upheld the same view and declared in his fatwa that,

⁸⁴⁵Ghanem, I, *Islamic Medical Jurisprudence*.(London, Isos Publications, 1982) p.276

⁸⁴⁶ al-Mahdi ,M, *Donation, Sale and Unbequeathed Possession of Human Organs. In The Islamic Vision of Some Medical Practices*. (Kuwait, K. al-Mazkur, A.al-Saif, A.R.al-Gindi and A.Abu-Ghudda, eds, IOMS Publications, 1989) p. 286

⁸⁴⁷ *Ibid*

⁸⁴⁸ Purport of the Senior Ulama Commission’s Decision, No.99, dated 6/11/1402 H. (1982 A.C.E.)

⁸⁴⁹ El-Shahat, Y. I. M, ‘ Islamic Viewpoint of Organ Transplantation’ (1999) 31 *Transplantation Proceedings*, 3271-3274 , p. 3271

“There are no judicial objections to the donation of cadaveric organs with the permission of the immediate family, for whoever needs these organs, considering also the desire for the redemption of the deceased.”

From this fatwa, it was re-emphasized that cadaver organ donations are allowed and have been given a ‘green light’, for the benefit of Muslims. However, the element of consent is still required before the procedures can take place.

On 4 January 1994, a similar fatwa was released from the Al-Azhar University in Cairo, approving organ donation from a recently deceased person to a patient in need of it. This fatwa also stressed in particular the need to get the prior approval of the donor him/herself while alive, or from his/her immediate relatives, and further concurred that there is no religious proof at all that such practices are forbidden⁸⁵⁰. Sheikh Ahmad Kutty preferred the consent requirement to be freely made by the donor him/herself prior to his/her death and further suggested that this could be done expressly through a will or by the donor signing a donor card. Only in cases where the donor did not signify his/her consent before his/her death would the deceased’s closest relatives be allowed to make the decision on the deceased’s behalf. As for the organ involved, it must be medically checked and verified as healthy and it should be capable of saving life or maintaining the quality of living of another human being. These organs must only be removed from the deceased party after death has been confirmed through reliable medical procedures⁸⁵¹.

Subsequently, the Head of the Azhar Islamic Institute, the Grand Mufti in Egypt, the Saudi Grand Ulama Council, the Grand Mufti in Kuwait and Iraq, Algiers Supreme Islamic Council and the Council of Islamic Ideology in Pakistan have all approved organ donation from dead persons accordingly⁸⁵². Recently, some religious authorities have waived the need to obtain family permission and allowed cadaver organs to be procured

⁸⁵⁰ *Ibid*

⁸⁵¹ Medical Fatawa dated 16 June 2006. *Islam’s View on Organ Transplants and Donations*. World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/> viewed on 4 February 2009

⁸⁵² Abdel Moneim Hassaballah, ‘Definition of Death, Organ Donation and Interruption of Treatment in Islam’ (1996) 11 *Nephrol Dial Transplant*, 964-965.

even if the deceased person had not made a declaration for organ donation⁸⁵³. These scholars have also exempted physicians from paying a legal penalty for removing organs in such cases⁸⁵⁴. Additionally, there are also claims that cadaveric organ donation is allowed even if the deceased person had made a declaration that any money obtained from the recipient must be spent paying off his/her debts or used for public welfare rather than just to save a life⁸⁵⁵.

7.6 THE PRACTICE OF ORGAN DONATION IN A FEW ISLAMIC COUNTRIES

Organ donation in Islamic Countries started at different paces. In the Middle East, for example, organ donation activities started in the mid-sixties and, even though the procedure is now regularly performed, there are still several countries that lack basic transplantation programmes⁸⁵⁶. Generally, most of the renal transplant programs started in the late 1970s and early 1980s⁸⁵⁷. Progress depended on a combination of many factors. It was partly related to the economic situation but also depended on other factors such as the religious rulings (fatwas) applicable⁸⁵⁸, societal outlooks and views⁸⁵⁹, the medical and surgical expertise, motivation⁸⁶⁰ and the governance of systems and law regulating it⁸⁶¹. In many Arab Muslim countries, organ donation is now considered by some as a “perpetual” charitable act⁸⁶². However, despite these positive assertions, there

⁸⁵³ Seyed R. Mousavi Shahid Behesti, ‘Ethical Considerations Related to Organ Transplantation and Islamic Law’ (2006) 4 *International Journal of Surgery* 91-93, p.92

⁸⁵⁴ *Ibid*

⁸⁵⁵ *Ibid*

⁸⁵⁶ Mustafa Al-Mousawi, ‘Organ Transplantation in the Middle East’ (2007) 39 *Transplantation Proceedings*, 785

⁸⁵⁷ Shaheen, F.A.M, Souqiyeh, M.Z, Ramprasad, K and Attar, M.B, ‘Current Issues and Problems of Transplantation in the Middle East: The Arabian Gulf’ (2001) 33 *Transplantation Proceedings*, 2621-2622

⁸⁵⁸ Shaheen FA, Al-Jondeby M, Kurpad R, and Al-Khader AA. Social and Cultural Issues in Organ Transplantation in Islamic Countries. (2004) 9 (2) *Ann. Transplant* 11-13.

⁸⁵⁹ Woo KT, ‘ Social and Cultural Aspects of Organ Donation in Asia’ (1992) *Ann Acad Med Singapore* May;21 (3): 421-427

⁸⁶⁰ Saieh-Andonie C, ‘The Management of End-Stage Renal Disease in Underdeveloped Countries: A Moral and an Economic Problem’ (1990) Mar; 4(2) *Pediatr Nephrol* 199-201.

⁸⁶¹ Seyed R. Mousavi Shahid Behesti, ‘Ethical Considerations Related to Organ Transplantation and Islamic Law’ (2006) 4 *International Journal of Surgery*, 91-93. p.91

⁸⁶² Gatrad, A R and Sheikh, A. ‘Medical Ethics and Islam: Principles and Practice’ (2001) 84 *Arch. Dis. Child*, 72-75. p.75.

are still some South Asia Muslim scholars (ulemas) and jurist (muftis), in Iran for example, who reject and oppose organ donation⁸⁶³ despite clear rulings available from religious leaders⁸⁶⁴. Their main reason for this opposition is that the human body is understood as an “*amanat*” (trusteeship) from *Allah* (God) and must not be desecrated following death. However, they support xenotransplantation and any research done in this area⁸⁶⁵. On the other hand, some other Islamic countries, such as Saudi Arabia, Iraq, Kuwait and Jordan, already have specific laws that legislate on cadaveric organ donations. Even more surprisingly, Egypt had already instated its law on corneal donation in 1959, although donation of other organs had not yet been formally approved⁸⁶⁶.

The problem of organ shortage also exists in these Islamic countries and this is very much related to the lack of legislation and the absence of organ donation organisations⁸⁶⁷. Countries of the Middle East, including the North African countries of Morocco, Algeria, Tunisia, Libya and Egypt, as well as Cyprus, Turkey, Iran, Pakistan, Jordan, Syria, Iraq, The Gulf Countries and Yemen are still trying to improve their organ donation rates⁸⁶⁸. Although there is a lot of diversity among these countries, they all show a predominance of living donations compared to cadaveric organ donation⁸⁶⁹. Another similarity is that these countries face religious and cultural challenges in promoting organ donation⁸⁷⁰.

As a result of the organ shortage, most patients in the Middle East needing organs such as livers, hearts and kidneys normally die, or travel to Europe or North America for life-

⁸⁶³ Bruzzone, P, ‘Religious Aspects of Organ Transplantation’ (2008) 40 *Transplantation Proceedings*, 1064-1067, p.1067

⁸⁶⁴ Seyed R. Mousavi Shahid Behesti, ‘Ethical Considerations Related to Organ Transplantation and Islamic Law’ (2006) 4 *International Journal of Surgery*, 91-93. p.92

⁸⁶⁵ Bruzzone, P, ‘Religious Aspects of Organ Transplantation’ (2008) 40 *Transplantation Proceedings*, 1064-1067, p.1067

⁸⁶⁶ Abdel Moneim Hassaballah, ‘Definition of Death, Organ Donation and Interruption of Treatment in Islam’ (1996) 11 *Nephrol Dial Transplant*, 964-965, p.965.

⁸⁶⁷ Mustafa Al-Mousawi, ‘Organ Transplantation in the Middle East’, (2007) 39 *Transplantation Proceedings*, 785

⁸⁶⁸ Daar, A.S, ‘The Evolution of Organ Transplantation in the Middle East’ (1999) 31 *Transplantation Proceedings*, 1070-1071

⁸⁶⁹ *Ibid*

⁸⁷⁰ *Ibid*

saving transplantations due to the shortage of deceased donors⁸⁷¹. This problem has also encouraged organ-trading and transplant tourism activities. Statistics show that there are only about 15 donors per million of population in the Middle East, compared to 27 in Europe and 52 in USA⁸⁷². However, the Middle East countries do have the advantage of an established organisation known as The Middle East Society for Organ Transplantation (MESOT), established in 1987. This MESOT regulates, discusses and elaborates between various transplant organisations in the Middle East while providing a platform to promote organ donation and addressing related problems faced collectively⁸⁷³. To further improve its functions, it is suggested that countries in the MESOT region should also set up a National Centre which coordinates all member countries⁸⁷⁴. This Centre should be financially supported by the community and should consider both cadaveric and living organ donations. Its main focus should be on the medical community, lay public and religious institutions, including gaining full support from the government of each country⁸⁷⁵.

a) SAUDI ARABIA

Saudi Arabia is an example of an Islamic country with an excellent record of organ donation, as hundreds of living-donor and cadaveric transplants of kidneys, liver, heart and other organs are performed every year⁸⁷⁶. Although once considered the most conservative Islamic country, Saudi Arabia has now advanced to become one of the most influential sources of ethical Islamic judicial views and rulings which expand and promote organ donation. It all started with the first resolution of the Islamic Council in Saudi Arabia (Senior Ulama Commission) on organ donation and transplantation, issued

⁸⁷¹ Mustafa Al-Mousawi, 'Organ Transplantation in the Middle East', (2007) 39 *Transplantation Proceedings*, 785

⁸⁷² *Ibid*

⁸⁷³ Mustafa Al-Mousawi, 'Organ Transplantation in the Middle East' (2007) 39 *Transplantation Proceedings*, 785

⁸⁷⁴ Shaheen, F.A.M and Souqiyeh, M.Z. 'Improving Transplantation Programs and Patient Care' (2005) 37 *Transplantation Proceedings*, 2909-2910

⁸⁷⁵ *Ibid*

⁸⁷⁶ Daar, A.S, 'The Evolution of Organ Transplantation in the Middle East' (1999) 31 *Transplantation Proceedings*, 1070-1071

in 1982⁸⁷⁷, which had cleared out ambiguities and confirmed that tissue and organ transplantation from both living and cadaveric donors is permissible and within the teachings of Islam. Their religious leaders, too, have no objections to its application⁸⁷⁸.

Saudi's model of organ donation activities includes having a national organ procurement centre which is run and supervised by a government agency⁸⁷⁹. Moving forward from this, Saudi started performing kidney, heart and liver transplants locally. Statistics published from the Saudi Centre for Organ Transplantation (SCOT) showed that 870 cadaveric and 780 living kidney transplants from relatives were performed in the Kingdom from 1988-1998⁸⁸⁰. Subsequently, this led to the formation of the National Kidney Foundation in 1985 which was later renamed the Saudi Centre of Organ Transplantation (SCOT). Its main tasks are quite similar, as it coordinates and establishes all activities related to transplantation⁸⁸¹. At the same time, SCOT was also responsible for setting strategies to improve awareness among the medical community and the public at large about the importance of having organ donation procedures taking place⁸⁸². A coordinated system between donating hospitals and the transplant centres was also set up to achieve this mission⁸⁸³.

SCOT had taken various approaches to improve the awareness of the medical community and the public at large on this issue. Within the medical community, it adopted steps such as providing training courses, making visits to donating hospitals, hosting conferences, releasing publications including journals, booklets, pamphlets, posters and books, and

⁸⁷⁷ El-Shahat, Y. I. M, 'Islamic Viewpoint of Organ Transplantation' (1999) 31 *Transplantation Proceedings*, 3271-3274, p. 3271

⁸⁷⁸ *Ibid*

⁸⁷⁹ Shaheen, FAM, Souqiyyeh MZ Attar MB, et al, 'The Saudi Centre for Organ Transplantation: An Ideal Model for Arabic Countries to Improve Treatment of End-Stage Organ Failure' (1996) 28 *Transplant Proceedings*, 247.

⁸⁸⁰ SCOT: Saudi (1998) 7 *J. Kid Dis Transplant*, 216.

⁸⁸¹ Al-Khader, A.A, and Shaheen, F, 'Strategies for Increasing Transplantation: the Saudi Experience' (1991) 31 *Transplantation Proceedings*, 3278

⁸⁸² Shaheen F.A.M, and Souqiyyeh, M.Z, 'Increasing Organ Donation Rates From Muslim Donors : Lessons From a Successful Model' (2004) 36 *Transplantation Proceedings*, 1878-1880, p.1878

⁸⁸³ *Ibid*

planning the curricula of medical schools and postgraduate hospital trainings⁸⁸⁴. For the public community at large, a slightly different approach applied as SCOT focused on holding public debates, utilizing the media, including television and local press, and distributing booklets and pamphlets. A few public surveys were also conducted and regular visits were made to schools as part of their promotion of organ donation⁸⁸⁵.

Saudi Arabia, through SCOT, had set up an efficient coordination and communication system equipped with supportive means of transportation to facilitate the movement of the transplant team, organs and recipients⁸⁸⁶. They also had a directory and an established system for organ distribution⁸⁸⁷. At the same time, their Islamic views on organ donation issues have always been a strong influence on and role model for other Muslim countries.

On organ-trading issues, Saudi Arabia has a clear stand, forbidding all kinds of organ sales including apparent emotionally related organ donation, and permitting only organ donation among genetically related individuals and spouses⁸⁸⁸. By the end of 2002, Saudi Arabia had successfully transplanted many organs locally, including 3,759 successful kidney transplants, 279 liver transplants, 92 heart transplants, 421 cornea transplants and 8 lung transplants, plus bone marrow, heart valve, skin and bone transplantations too⁸⁸⁹. Undeniably, Saudi Arabia is currently the leading Islamic country in organ donation and the survival rates are excellent⁸⁹⁰.

⁸⁸⁴ Ganikos, ML, McNeil C, Braslow, JB, et al, 'A Case Study in Planning for Public Health Education: The Organ and Tissue Donation Experience' (1994) *Public Health Rep.* 109:626,

⁸⁸⁵ Bidigare, SA and Oermann, MH, 'Attitudes and Knowledge of Nurses Regarding Organ Procurement' (1991) *Journal of Acute & Critical Care*, Heart Lung 20:20-4

⁸⁸⁶ Rowinski, W, Ostrowski, K, Adadynnski L, et al. 'Factors Limiting Renal Transplantation Program in Poland' (1996) *Ann. Transplant* 1:18

⁸⁸⁷ Shaheen F.A.M, and Souqiyyeh, M.Z, , 'Increasing Organ Donation Rates From Muslim Donors: Lessons From a Successful Model' (2004) 36 *Transplantation Proceedings*, 1878-1880, p.1880

⁸⁸⁸ Rasheed, HZ, 'Organ Donation and Transplantation- A Muslim View Point' (1992) 24 *Transplant Proceedings* 2116.

⁸⁸⁹ F.A.M. Shaheen and M.Z. Souqiyyeh, 'Increasing Organ Donation Rates from Muslim Donors: Lessons From A Successful Model' (2004) 36 *Transplantation Proceedings*, 1878-1880, p.1880.

⁸⁹⁰ Al-Khader , A.A. and Shaheen, F. 'Strategies for Increasing Transplantation: The Saudi Experience' (1991) 31 *Transplantation Proceedings*, 3278

b) UNITED ARAB EMIRATES

The United Arab Emirates (U.A.E) had passed their own law to regulate organ donation matters in 1993⁸⁹¹. These laws were based on the Islamic principles and many existing fatwas on the issue. Among others, Article No.1 mentioned that medical specialists are allowed to remove organs from a living person or someone recently deceased and can transplant them into a patient as a form of treatment to save his/her life. However, this must be performed according to the conditions and procedures of the law specified therein. There are also provisions touching on living related donation where a few conditions that must be fulfilled were laid down. Among others, it requires both the living donor and the recipient to have a blood relationship of not less than the second degree, or the donor should be a wet nurse or her children or spouse. These relationships should be attested to by specialised official organisations. The donor is also required to be in good health, both physically and psychologically, and certain medical examinations will be performed to confirm this. However, a case of living donation can only take place if it can be guaranteed that it will not be harmful to the parties, both donor and recipient. Donation of a single organ such as the heart is not allowed as the donor him/herself is dependent and needs that organ too.

As for the donor him/herself, the act of donating organs must be done without any social or financial pressure being exerted. Written consent must be obtained and signed by the donor him/herself and he/she has full rights to change his/her mind at any time before the surgery commences. The donor must also be fully informed of any possible risks and hazards that might arise due to the donation and all this must be documented in his/her medical file. The U.A.E. Transplantation Law also has a provision which protects the position of the organ recipient by not allowing the organ donor to later reclaim his/her organs. In cases of cadaveric organ donation, there are also certain conditions to be adhered to. Firstly, there must be confirmation and documentation of brain death which is done by following the procedures laid down in the brain death documentation form. In order to avoid conflict of interest, it is a requirement that the medical team involved in the organ donation procedures must not be the same ones diagnosing and confirming the

⁸⁹¹ Federal Law No.15/1993

brain death of the patient. Consent for organ donation should be obtained from the relatives of the brain-dead patient and must be obtained in accordance with the special consent form. Alternatively, if the brain-dead patient cannot be identified, consent from the official specialised organisation should be obtained before the organs are taken. However, if there is any evidence of refusal to donate organs which had been expressed by the deceased in his/her will when he/she was still alive, and that particular will has been attested by two witnesses, harvesting of any of his/her organs is totally prohibited.

The law in U.A.E. also prohibits organ-trafficking or any act of seeking financial gain from organ donation activities. Related to this point, the physicians involved are forbidden to proceed with the donation if they have knowledge that it is being done for any financial gain at all. However, solid evidence is needed to prove this. There are also penalties in the form of imprisonment and/or fines (not more than DHs.30, 000) for those who are found guilty of organ-trafficking and the punishment will be doubled if the same person commits the same crime again within a two-year period.

c) EGYPT

There was some delay in the acceptance and practice of organ donation activities in Egypt. Not only does it lack any federal policy on transplantation, but no national procurement and organ distribution system is in existence either⁸⁹². Islamic jurists, including great scholars, still conflict in their views on organ donation in particular. For example, Sheikh Mohamed Mutwali al-Sharawi, a popular religious leader well-known in the Muslim world, condemns organ donation in humans and claims it is a misuse of our bodies, which belong to God, while treating it as an attempt to change God's will. On the other hand, Sheikh Mohamed Sayed Tantawi, the Grand Sheikh of Al-Azhar Mosque and University, consents to organ donation activities provided they are done to save another person's life⁸⁹³. To make things worse, not even the medical profession itself has reached agreement on accepting organ donation⁸⁹⁴, or on the concept of brain death⁸⁹⁵. Therefore,

⁸⁹² Debra Budiani, 'Facilitating Organ Transplants in Egypt: An Analysis of Doctors' Discourse', (2007) *Body & Society*, Vol. 13(3), 125-149, p.125

⁸⁹³ *Ibid*, p.131.

⁸⁹⁴ *Ibid*, p.134

the 'People's Council' (Parliament) has delayed the approval of the necessary law which has actually been under discussion since 1991⁸⁹⁶.

Although Egypt does allow living organ donations, this divergence of opinion between two major religious leaders has caused the country to become paralyzed in its capacity to develop cadaveric donations, resulting in more than 30% of its state budget for secondary healthcare going towards dialysis treatments alone⁸⁹⁷. Subsequently, the prohibition of the procurement of cadaveric organs has resulted in living donors becoming the only source available⁸⁹⁸ and organ supply becoming even scarcer. However, Egypt does open its doors to unrelated living donations taking place. It was reported that, in the early 1990s, 75% of the donations taking place involved unrelated living donors⁸⁹⁹. Apart from the absence of a national distribution system for organs and small numbers of related living donations taking place, other factors hindering Egypt's progress are the patient's inability to afford the transplant surgery and also the high price put on each organ⁹⁰⁰.

The impact of inadequate legislation regulating organ transplants has also turned Egypt into a centre for the illicit organ trade⁹⁰¹ where up to 95% of the 3000 legal kidney transplants per year, and hundreds of illegal ones, involve a commercial transaction⁹⁰². Kidneys sourced from live donors are sourced by organ brokers, from young Egyptians who are desperate to sell their kidneys to pay off debts or cope with the high cost of

⁸⁹⁵ Abdel Moneim Hassaballah, 'Definition of Death, Organ Donation and Interruption of Treatment in Islam' (1996) 11 *Nephrol Dial Transplant* 964-965, p.965.

⁸⁹⁶ *Ibid*

⁸⁹⁷ Daar, A.S, 'The Evolution of Organ Transplantation in the Middle East' (1999) 31 *Transplantation Proceedings*, 1070-1071

⁸⁹⁸ Debra Budiani, 'Facilitating Organ Transplants in Egypt: An Analysis of Doctors' Discourse', (2007) *Body & Society*, Vol. 13(3): 125-149, p.125

⁸⁹⁹ Barsoum, R. and M.A.Bakr, 'The Egyptian Renal Transplant Experience', (2000) *Clinical Transplants* 359-360

⁹⁰⁰ Debra Budiani, 'Facilitating Organ Transplants in Egypt: An Analysis of Doctors' Discourse', (2007) *Body & Society*, Vol. 13(3): 125-149, p.129

⁹⁰¹ Joseph Mayton, 'Egypt Passes New Organ Transplant Law', 2 March 2010, <http://bikyamasr.com/wordpress/?p=9227>, viewed on 25 March 2011.

⁹⁰² 'China, UK, Egypt, Colombia: Crackdown on Organ Transplant Medical Tourism', 18 August 2009, *International Medical Travel Journal*, http://www.imtj.com/news/?EntryId82=152016&sms_ss=email&at_xt=4d8ff4d5eab002aa, viewed on 28 March 2011.

living⁹⁰³: a kidney can be worth \$2,185⁹⁰⁴. As a result of all this, in early 2010, the Egyptian Parliament voted overwhelmingly to pass new laws regulating organ transplant issues, including curbing illegal organ trafficking and tourism⁹⁰⁵. The new law has not only banned commercial trade in organs, but has also barred transplants between Egyptians and foreigners, except in cases of spouses⁹⁰⁶. All organ transplant financing will be provided by the government, particularly in government-run hospitals⁹⁰⁷. However, although the definition of death is not given, any cases of potential organ donation from deceased persons must be referred to a panel of three experts, who are appointed by the Higher Committee for Organ Transplants, an affiliated body under the Ministry of Health⁹⁰⁸. This panel must reach a consensus on whether the potential donor is dead because any removal of organs without the approval of the panel will be considered as first-degree murder punishable by death⁹⁰⁹.

d) IRAN

Organ donation has been practised in Iran for a long time. Avicenna was the great Iranian physician who performed the first nerve repairs and, to this day, Iran has had one of the most successful transplantation programmes in the Middle East region, including multi-organ transplantations⁹¹⁰. One unique feature of the Iranian model of organ donation scheme is that it allows renal graft donation from living unrelated persons⁹¹¹ and emotionally related donors⁹¹² to patients with end-stage renal disease. So, spouses or close friends who are willing to donate will undergo psychiatric and medical evaluation

⁹⁰³ *Ibid*

⁹⁰⁴ Mullins, K.J, 'Egypt's Poor Selling Organs To Survive', 28 December 2009, *Digital Journal*, <http://www.digitaljournal.com/article/285611>, viewed on 28 March 2011.

⁹⁰⁵ Joseph Mayton, 'Egypt Passes New Organ Transplant Law', 2 March 2010, <http://bikyamasr.com/wordpress/?p=9227>, viewed on 25 March 2011.

⁹⁰⁶ *Ibid*

⁹⁰⁷ *Ibid*

⁹⁰⁸ 'WHO Welcomes Egyptian Organ Transplant Law', 20 January 2010, <http://www.emro.who.int/pressreleases/2010/no2.htm>, viewed on 28 March 2011

⁹⁰⁹ *Ibid*

⁹¹⁰ Larijani, B., Zahedi F, and Taheri, E, 'Ethical and Legal Aspects of Organ Transplantation in Iran' (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1241.

⁹¹¹ Zargooshi J, 'Quality of Life of Iranian Kidney 'Donors' (2001) *J.Urol*, 166:1790.

⁹¹² Behzad Einollahi, 'Iranian Experience With The Non-Related Renal Transplantation', (2004) 15(4) *Saudi J Kidney Dis Transplant*, 421-428, p.422

to ensure their motivation and rule out any elements of coercion⁹¹³. Another important aspect of Iranian law on organ transplantation is the prevention of commercial dealings⁹¹⁴, though it does have a reward system applicable.

Having been much updated legally, Iran also has the “Organ Transplantation and Brain Death Act”, approved in 2000 by the parliament⁹¹⁵, which specifically requires that brain death be diagnosed and certified by four physicians, namely a neurologist, a neurosurgeon, a medical specialist and an anaesthesiologist. Similarly to the practice in the United Arab Emirates, the same members of the medical team that diagnosed and established brain death of a particular patient are not allowed to be part of the transplantation team. However, in all cases, consent from the deceased, which had been made earlier, must be obtained either in a written form or through a signed donor card. Alternatively, in cases where there is no express consent of the deceased, the consenting authority is extended to the next of kin.

In Iran, leading religious scholars have issued rulings that expressly allow cadaver and living donations to take place. However, due to social and cultural factors, cadaver organ donations are still not as popular⁹¹⁶ as living donations. There are recent fatwas available in Iran by leading scholars that mentioned the following:

- 1) paying *diyyah* (a fine for harm to the body) or for *museh* (disfigurement of the dead);
- 2) harvesting of cadaver organs from someone who has not made a *wasiyah* (will);
- 3) whether family permission (by next of kin or the inheritor of the deceased) could be waived; and

⁹¹³ Behzad Einollahi, ‘Iranian Experience With The Non-Related Renal Transplantation’, (2004) 15(4) Saudi J Kidney Dis Transplant, 421-428, p.422

⁹¹⁴ Larijani, B., Zahedi F, and Taheri, E, ‘Ethical and Legal Aspects of Organ Transplantation in Iran’ (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1243

⁹¹⁵ Iran Parliament. Deceased or Brain Dead Patients Organ Transplantation Act. H/24804-T/9929, 6-4-2000.

⁹¹⁶ Raza, M, and Hedayat, K.M, ‘Some Sociocultural Aspects of Cadaver Organ Donation: Recent Rulings from Iran’ (2004) 36 *Transplantation Proceedings*, 2888-2890, p.2888

4) whether cadaver organs could be harvested if the donor specifies that remuneration from the recipient should be granted for the purpose of general public benefit or to pay donor debts⁹¹⁷.

In reference to the above, it seems that, in a situation where there is no family member available or when it is difficult to get permission and time is running short to save a person's life, it is not necessary to obtain permission first. And, if someone has made a will specifying that his/her organs should be harvested after death, it is considered totally legal to remove those organs, even to the extent of disregarding family objections in order to save another Muslim's life. Even the physician who performed the transplantation will be totally exempted from making the *diyyah* payment⁹¹⁸.

In cases where the deceased did not want to donate his/her organs, but his/her family wished to, the family is then allowed to make the decision according to their own wishes, as long as it is done with the intention to save a life⁹¹⁹. This practice actually provides family members of the deceased with full authority to overrule and even decide on behalf of the deceased. There are also provisions which allow organ donation to be turned into a source of debt payment, or charitable acts, or any other obligatory acts on behalf of the deceased. Therefore, if a person dies, in accordance with his/her will or his/her family's permission, his/her transplantable organs may be removed to pay off debts or for charitable purposes⁹²⁰. Interestingly, a person can also make a will stating that, after his/her death, some or all of his/her organs may be sold for treatment or medical education and that the proceeds should be spent on charitable works in that person's name⁹²¹.

Until 1988, all living donors had to be related to the recipient. However, as the number of required organs increased, a controlled living unrelated donor programme was introduced

⁹¹⁷ *Ibid*

⁹¹⁸ *Ibid*

⁹¹⁹ *Ibid*

⁹²⁰ *Ibid*, p.2889

⁹²¹ *Ibid*

in 1990⁹²², which eventually managed to eliminate the waiting list in 1999⁹²³ and positively remove black market profiteering⁹²⁴. Later, special partnerships were made between the government and various charitable groups to compensate living unrelated donors through governmental awards⁹²⁵. In 1997, the government of Iran approved the law related to the gift of organ donation, particularly kidneys. The “rewarded gifting”, reimbursed through a non-governmental organisation, the Charity Foundation of Special Diseases, could be considered a cost-effective system that also revolutionized the distribution of organs⁹²⁶. All organ donation procedures must take place in governmental university hospitals and all hospital expenses are paid by the government⁹²⁷. There are no “middle men” involved and great precautions are taken to ensure all medical aspects are completely adhered to⁹²⁸. However, this system is only available to Iranians, as foreigners are not allowed to undergo organ donation under this scheme⁹²⁹. Here, patients confirmed as having end-stage renal disease (ESRD) will be automatically referred to the Society for Supporting Dialysis and Transplantation Patients⁹³⁰. Donors are required to be healthy, aged between 18 and 35 and to have obtained permission from their parents or spouse to register. This permission requirement is mandatory and must be obtained before they are later introduced to their potential organ recipients⁹³¹.

⁹²² Behzad Einollahi, ‘Iranian Experience With The Non-Related Renal Transplantation’, (2004) 15(4) *Saudi J Kidney Dis Transplant*, 421-428, p.423

⁹²³ Larijani, B., Zahedi F, and Taheri, E, , ‘Ethical and Legal Aspects of Organ Transplantation in Iran’ (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1242

⁹²⁴ Raza, M and Hedayat, K.M, Some Sociocultural Aspects of Cadaver Organ Donation: Recent Rulings From Iran. *Transplantation Proceedings*, 36, 2888-2890 (2004). p.2889

⁹²⁵ Larijani, B., Zahedi F, and Taheri, E, ‘Ethical and Legal Aspects of Organ Transplantation in Iran’ (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1242

⁹²⁶ Raza, M and Hedayat, K.M, Some Sociocultural Aspects of Cadaver Organ Donation: Recent Rulings From Iran. *Transplantation Proceedings*, 36, 2888-2890 (2004). p.2889

⁹²⁷ Larijani, B., Zahedi F and Taheri, E, , ‘Ethical and Legal Aspects of Organ Transplantation in Iran’ (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1242

⁹²⁸ *Ibid*

⁹²⁹ *Ibid*

⁹³⁰ Behzad Einollahi, ‘Iranian Experience With The Non-Related Renal Transplantation’, (2004) 15(4) *Saudi J Kidney Dis Transplant*, 421-428, p.423

⁹³¹ *Ibid*

By virtue of this ‘Iran Model’, organ donation programmes developed rapidly and the government provided funds in spite of the large demand, lack of cadaver donors, high cost of transplantation abroad, safety of kidney donation and availability of volunteers⁹³². Looking at the other side of the story, this system also has some negative impacts, as it has now become a common phenomenon for many young donors and impoverished Iranians to agree to donate organs in order to pay off their debts. There have been real cases reported where some donors later confess their feelings of regret as, consequently, they now suffer from health problems and long-term psychological issues⁹³³. The system does seem to fuel assumptions that organ donation of this kind is not really done as an act of altruism and voluntariness, but is caused by people’s state of poverty and is part of their effort to gain government incentives⁹³⁴. A study proved that all unrelated renal donations taking place were from low or middle socioeconomic classes; 84% of them were categorized as poor and the remaining 16% were from middle-class society⁹³⁵. However, to balance this fact it must also be noted that even related donors are rewarded for donating their kidneys⁹³⁶. It is just that unrelated donation is more popular, even among the poor, as most of the recipients are reluctant to burden their own family members and impose any emotional or physical pressure on them. As a result, they prefer to resort to unrelated donors for the needed organs⁹³⁷.

Now, however, Iran is gradually moving towards promoting cadaveric organ donation – there was already a fatwa approving this even before the year 2000. Additionally, in April 2000, Iran passed a law justifying cadaveric donation after brain death. However, Iran still faces a challenge to overcome the fact that, despite these rulings, many Iranians are still reluctant to allow cadaveric organ donations to take place. Iran has yet to increase

⁹³² *Ibid*

⁹³³ Raza, M and Hedayat, K.M, Some Sociocultural Aspects of Cadaver Organ Donation: Recent Rulings From Iran. *Transplantation Proceedings*, 36, 2888-2890 (2004). p.2889

⁹³⁴ Larijani, B.Zahedi F and Taheri, E, ‘Ethical and Legal Aspects of Organ Transplantation in Iran’ (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1242

⁹³⁵ Ghods AJ, Ossareh S, Khosravani P, ‘ Comparison of Some Characteristics of Donors and Recipients in a Controlled Living Unrelated Donor Renal Transplantation Program’ (2001) 33 *Transplantation Proceedings*, 2626

⁹³⁶ Larijani, B.Zahedi F and Taheri, E, ‘Ethical and Legal Aspects of Organ Transplantation in Iran’ (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1242

⁹³⁷ *Ibid*

public awareness among its people while at the same time providing better medical equipment and laboratory facilities to gain the public's confidence⁹³⁸. Hopefully, by having legal mechanisms regulating cadaveric donations, including receiving full support from religious authorities locally⁹³⁹, the cadaveric donation programme will successfully expand and be able to supply the needed organs. This again proves that religious beliefs and rulings can help influence the success of any transplantation system at the public level⁹⁴⁰. There has also been a suggestion to establish a National Transplant Registry. Currently, the Iranian Network for Organ Procurement, which is related to the Ministry of Health and Medical Education, is the organisation with the responsibility for supervising and coordinating all transplantation activities in Iran. Besides that, a lot of effort, such as providing post-operative medical insurance plans for donors and motivating the public through the mass media to increase awareness of organ donation, has been geared towards achieving this aim⁹⁴¹.

e) PAKISTAN

Religious and cultural values are two important elements well guarded by the Pakistani people. This justifies the fact that, even among the medical community itself, there is always a growing desire to trace and discover more about the Muslim history within contemporary discourse of Muslim scholars and *ulamas* in providing their treatment to the public at large⁹⁴². Renal transplantation began in the 1980s with living related donors in the public sector⁹⁴³. However, factors such as having more expertise in private clinics, lack of facilities in the public sector, absence of transplant laws prohibiting organ-trading and organ shortage problems led to living unrelated donor transplants emerging in the

⁹³⁸ *Ibid*

⁹³⁹ Raza, M and Hedayat, K.M, 'Some Sociocultural Aspects of Cadaver Organ Donation : Recent Rulings From Iran' (2004) 36 *Transplantation Proceedings*, 2888-2890, p.2889

⁹⁴⁰ *Ibid*

⁹⁴¹ Larijani, B.Zahedi F and Taheri, E, 'Ethical and Legal Aspects of Organ Transplantation in Iran' (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1244

⁹⁴² Bruzzone, P, 'Religious Aspects of Organ Transplantation' (2008) 40 *Transplantation Proceedings*, 1064-1067, p.1066

⁹⁴³ Syed Adibul Hasan Rizvi, Syed Ali Anwar Naqvi, Mirza Naqi Zafar, Farida Mazhar, Rana Muzaffar, Rubina Naqvi, Fazal Akhtar and Ejaz Ahmed, 'Commercial Transplants in Local Pakistanis From Vended Kidneys: A Socio-Economic and Outcome Study', (2009) *Transplant International*, Sindh Institute of Urology and Transplantation Journal Compilation ©2009 European Society for Organ Transplantation

private sector from kidney vendors⁹⁴⁴. Most of these vendors are society's poor and impoverished people who sell their kidneys to earn money to gain freedom from bondage or to pay off their loans⁹⁴⁵. The Pakistan model of organ donation provides an example of where charitable funding programmes manage end-stage organ failure in a developing-country setting⁹⁴⁶.

With a population of 140 million, most of whom live in poverty, Pakistan provides dialysis, living related kidney transplantations and immunosuppressive drugs⁹⁴⁷ free of cost irrespective of the socioeconomic status of the patient⁹⁴⁸. However, no cadaveric organ procurement and transplantation programme has been made available, due to cultural and religious beliefs⁹⁴⁹. Cadaveric organ procurement seems impossible to establish as there has been a lack of will on the part of the Pakistani legislature to discuss and approve an organ transplantation bill since 1992⁹⁵⁰. That is why only living kidney donations are practised, commonly between blood-related donors chosen from within extended-family members⁹⁵¹. This negative impact of not having a cadaver organ programme causes the medical staff great stress in fulfilling their responsibility to obtain the necessary kidneys for their patients⁹⁵². However, following the intervention by the Supreme Court of Pakistan in July 2007, an ordinance to regulate organ transplantation and curb kidney trading was drafted by the Ministries of Health and Law⁹⁵³. The Transplantation of Human Organs and Tissues Ordinance 2007 which was later promulgated as the Transplantation of Human Organ and Tissues Act 2009 Act regulated

⁹⁴⁴ *Ibid*

⁹⁴⁵ Navqi S.A.A, Ali B, Mazhar F, Zafar MN, Rizvi SAH, 'A Socio-Economic Survey of Kidney Vendors In Pakistan', (2007) 20 *Transplant International*, 934

⁹⁴⁶ Rizki SA, Naqvi SA, Zafar MN, 'Renal Transplantation in Pakistan' (2002) *Clin. Transpl* 191.

⁹⁴⁷ Syed Adibul Hasan Rizvi, Syed Ali Anwar Naqvi, Mirza Naqi Zafar, Farida Mazhar, Rana Muzaffar, Rubina Naqvi, Fazal Akhtar and Ejaz Ahmed, 'Commercial Transplants in Local Pakistanis From Vended Kidneys: A Socio-Economic and Outcome Study', (2009) *Transplant International*, Sindh Institute of Urology and Transplantation Journal Compilation ©2009 European Society for Organ Transplantation

⁹⁴⁸ Farhat Moazam, *Bioethics and Organ Transplantation in a Muslim Society* (2006, Indiana University Press, Bloomington and Indianapolis) p.216

⁹⁴⁹ *Ibid*

⁹⁵⁰ *Ibid*

⁹⁵¹ *Ibid*

⁹⁵² *Ibid*, pp. 220-221

⁹⁵³ Bile, K.M, Qureshi, J.A.R.H, Rizvi, S.A.H, Navqi, S.A.A, Usmani, A.Q, and Lashari, K.A, Human Organ and Tissue Transplantation in Pakistan: When a Regulation Makes a Difference, (2010) *Eastern Mediterranean Health Journal*, Vol.16, Supplement

the removal, storage and transplantation of human organs and tissues for therapeutic purposes and related procedural matters all over Pakistan⁹⁵⁴. It clearly stipulated that a donor should not be less than 18 years of age, every donation must be made voluntarily and donation should be permissible to a living person genetically and legally related⁹⁵⁵. However, in the case of non-availability of a close blood relative donor, the organ transplantation evaluation committee⁹⁵⁶ has the prerogative to allow donation by non-close blood relative donors after ensuring that such donation was voluntarily made. Subsequently, commercial dealings in human organs are rendered an offence, punishable with imprisonment for up to ten years along with a monetary penalty⁹⁵⁷.

7.7 ISLAM AND BRAIN DEATH

Islam holds that man consists of two essential elements: the body and the soul. Life exists in the human body as long as the soul is joined to it and it ceases when the soul departs from the body⁹⁵⁸. Looking back in history, the ancient medical doctors often associated death with certain physical signs based on their medical observations and knowledge. This includes lack of consciousness, loss of body temperature, cessation of pulse and breathing, glazing of the eyes, parting of the lips, sagging of the nose and slackening in

⁹⁵⁴ Transplantation of Human Organ and Tissues Act 2009, http://www.na.gov.pk/passed_bill/transplantation_human_organ_act_2009_121109 pdf-viewed on 25 May 2011

⁹⁵⁵ Section 3 of the Act- The term “close blood relative” which is defined as parent, son, daughter, sister and brother, and included spouse, provides that the transplantation must voluntary, motivated and free of duress or coercion-Section 3 (a) of the Act.

⁹⁵⁶ The evaluation committees are constituted through the legislation and consist of surgical, medical and transplantation specialists, nephrologists, a neurophysician and an intensivist where available, including two local notables with a good record of social service. They are accountable for:

- a) exercising control over transplantation procedures in medical institutions and hospitals for ensuring that no organ or tissue are retrieved from non-related living donor without prior approval of the evaluating committee;
- b) determining brain death of a person;
- c) determining propriety of removal of a human organ from any living person using brain death protocol; and
- d) determining fitness or otherwise for transplantation of a human organ into any other body-Section 5 (1) of the Act

⁹⁵⁷ Bile, K.M, Qureshi, J.A.R.H, Rizvi, S.A.H, Navqi, S.A.A, Usmani, A.Q, and Lashari, K.A, Human Organ and Tissue Transplantation in Pakistan: When a Regulation Makes a Difference, (2010) *Eastern Mediterranean Health Journal*, Vol.16, Supplement

⁹⁵⁸ ‘The Muslim Law (Shariah) Council and Organ Transplants’ (1996) 4 *Accident and Emergency Nursing*, 73-75. p.73

muscles of the hands and feet⁹⁵⁹. Soon after, many Muslim scholars started to understand that death is the cessation of all bodily (not cellular) activities including breathing, movement, hearing, talking and beating of the heart⁹⁶⁰. Only later did some Muslim medical experts define death in an individual as occurring when one of the following two situations exists:

- 1) Complete irreversible cessation of respiratory and cardiovascular systems; or
- 2) Complete irreversible cessation of the functions of the brain including the brainstem⁹⁶¹.

Nevertheless, in both situations above, death must still be confirmed by the accepted medical standards. In cases of brain death in particular, it is necessary to have the presence of a reliable medical specialist, well-experienced in the clinical diagnosis of brain death and brainstem death, including the various implications of such diagnosis⁹⁶².

Although, in the beginning, the heart was believed to be the most important organ related to life and death, this perception has now further developed and changed to considering the brain to be the central and crucial part which controls the entire body and its functions. Thus, when the brain is damaged either partially or in total, the body will definitely suffer deterioration⁹⁶³. Consequently, the main factor in proclaiming death nowadays is the lifelessness of the brainstem which controls and regulates vital bodily functions⁹⁶⁴. In cases where other vital organs, such as the heart, malfunction or temporarily stop, as long as the brainstem is still alive, the said organ might still be revived. However, once the brainstem itself has died, there is no hope of saving the patient and, medically, death is then ascertained. Muslim jurists are also inclined to this

⁹⁵⁹ *Ibid*

⁹⁶⁰ Proceedings of the seminar, "Beginning and End of Life According to Teachings of Islam" held by the Islamic Organization for Medical Sciences, Kuwait, January 1985.

⁹⁶¹ Muzammil Siddiqi, Medical Fatawa dated 21 June 2006, *Who Takes a Patient's Life?* World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/> viewed on 4 February 2009.

⁹⁶² *Ibid*

⁹⁶³ 'The Muslim Law (Shariah) Council and Organ Transplants' (1996) 4 *Accident and Emergency Nursing*, 73-75, p.73.

⁹⁶⁴ Medical Fatawa dated 20 June 2006, *Death That Justifies Switching Off Life Support*. World Fatwa Management and Research Institute Islamic Science University Of Malaysia. <http://infad.usim.edu.my/>, Viewed on 4 February 2009

view and certain rulings about the dead follow once this situation is applicable⁹⁶⁵. Following this situation, the moment brainstem death is certified by a committee of medical specialists, it automatically becomes lawful to switch off the life support systems⁹⁶⁶.

The International Council of Muslim Doctors upholds and supports a similar view that death is completed by brain death and not by heart cessation⁹⁶⁷. The “Academy of Islamic Jurisprudence” at the Third International Conference of Islamic Jurists, which constitutes members from several Islamic countries, held in Amman, Jordan, acknowledged the concept of brain death in October 1986⁹⁶⁸ and equated brain death with cardiac and respiratory death⁹⁶⁹. Their fatwa declared the following:

“A person (is) considered legally dead and all the Shariah’s principles (Islamic Law) can be applied when one of the following signs is established:

i) Complete stoppage of the heart and breathing which are decided to be irreversible by doctors.

ii) Complete stoppage of all vital functions of the brain which are decided to be irreversible by doctors and the brain has started to degenerate.

Under these circumstances it is justified to disconnect life supporting systems even though some organs continue to function automatically (e.g. the heart) under the effect of the supporting devices”⁹⁷⁰.

Dr. Sheikh Muhammed Tantawi explains that the Islamic view of death is actually the departure of the soul from the body,⁹⁷¹ which will consequently result in death. This incident is not an observable phenomenon, like the seizure of brain functions or stopping

⁹⁶⁵ *Ibid*

⁹⁶⁶ *Ibid*

⁹⁶⁷ *Ibid*

⁹⁶⁸ Declaration of the Academy of Islamic Jurisprudence, Third Meeting, Amman, Jordan, October 1986.

⁹⁶⁹ Abdel Moneim Hassaballah, ‘Definition of Death, Organ Donation and Interruption of Treatment in Islam’ (1996) 11 *Nephrol Dial Transplant*, 964-965, p.965.

⁹⁷⁰ Fatwa No.V (Religious Proclamation) of the “Academy of Islamic Jurisprudence” at the Third International Conference of Islamic Jurists held on October 1986.

⁹⁷¹ El-Shahat, Y. I. M, ‘Islamic Viewpoint of Organ Transplantation’ (1999) 31 *Transplantation Proceedings*, 3271-3274, p. 3271

of the heart⁹⁷². However, it is agreed that the burden of confirming that this ‘departure’ has taken place must be laid upon the medical professionals to further ensure and certify death medically and clinically.

As Islam promotes the protection and preservation of life, no-one is authorised to deliberately end life, be it one’s own or that of another human being⁹⁷³. However, even though saving life is encouraged, artificial prolongation of life is not within the Islamic realm unless there is evidence that a reasonable quality of life will result from it⁹⁷⁴. Dr Tantawi also emphasized that “the Muslim Muftis are not involved in this and will not become involved”⁹⁷⁵. So, once a few medical experts determine that a patient is terminally ill and that there is no longer any hope for recovery, it will be permissible for them to stop any subsisting medication⁹⁷⁶. If the patient is on life support, it may be permissible, with due consultation and care, to decide to switch off the life support machine. In these cases, the switching-off of the life support machine does not fall under the prohibition of euthanasia, since brain-dead patients are actually already dead and removal of the life support machine is only intended to allow nature to take its course⁹⁷⁷.

Despite that, Dr. Muzammil H. Siddiqi, President of the Fiqh Council of North America, emphasized that due consultation and care must be taken before the decision is made to switch off the life support machine in all cases⁹⁷⁸. According to Dr. Tantawi, in cases where the patient’s heart continues to beat only because he/she is attached to the life support machine and he/she has been diagnosed as brain-dead, there is no blame attached

⁹⁷² Jonathan E. Brockopp, ‘Islamic Ethics of Saving Life: Legal and Moral Guidelines’ 21 (2002) *MEDLAW* 225. p.228

⁹⁷³ Gatrad, A R, and Sheikh, A, ‘Medical Ethics and Islam: Principles and Practice’ (2001) 84 *Arch. Dis. Child*, 72-75. p.74.

⁹⁷⁴ Rahman F, *Health and Medicine in the Islamic Tradition* (Chicago, ABC, 1998) 108-9.

⁹⁷⁵ El-Shahat, Y. I. M, ‘Islamic Viewpoint of Organ Transplantation’ (1999) 31 *Transplantation Proceedings*, 3271-3274, p. 3271

⁹⁷⁶ Medical Fatawa dated 26 June 2007, *Is Euthanasia Allowed in Islam?* World Fatwa Management and Research Institute Islamic Science University Of Malaysia. <http://infad.usim.edu.my/> viewed on 4 February 2009

⁹⁷⁷ Jonathan E. Brockopp, ‘Islamic Ethics of Saving Life: Legal and Moral Guidelines’ (2002) 21 *MEDLAW* 225. p.230

⁹⁷⁸ Medical Fatawa dated 21 June 2006, *Can the State Intervene to Determine the Life of Individuals?* World Fatwa Management and Research Institute Islamic University of Malaysia. <http://infad.usim.edu.my/> viewed on 4. February 2009.

to the family for requesting the removal of the machine⁹⁷⁹ as this does not induce death, which is clearly prohibited in Islam⁹⁸⁰. Additionally, the Council of Islamic Jurisprudence, in its third session, after considering comprehensive explanations from consultant doctors, decided that all *Shariah* principles concerning death could be applied when one of the following signs was confirmed:

- a) Complete cessation of the heart or respiration, including the decision of consultant doctors that the cessation is irreversible; or
- b) Complete cessation of all functions of the brain, including the decision of consultant doctors that the cessation is irreversible and that the brain has started to degenerate.

When either of these conditions is met, it is considered permissible to disconnect the supportive means from the patient, even though some of his/her organs continue functioning artificially (i.e. the heart)⁹⁸¹. Dr. Yusuf Qaradawi, during the First GCC Organ Transplantation Congress in Abu-Dhabi, in February 1998, declared in his fatwa that,

“A person who has been diagnosed as brain-dead is considered completely dead in the eyes of Islamic jurisprudence, making possible organ donorship from him to another patient in need. It is allowable to remove the needed organs before life support systems have been disconnected”⁹⁸².

A study conducted in six Islamic countries - Kuwait, Saudi Arabia, Iran, Egypt, Lebanon and Oman - with 32 senior Muslim scholars resulted in 29 respondents (90.6%) initially rejecting the brain death concept, as well as not allowing the discontinuation of life support in brain-dead patients; but after 9 scholars were directly approached and exposed to the real concept of brain death, 7 changed their view and subsequently accepted the

⁹⁷⁹ “The Rector of al-Azhar to Physicians: Concerning You and Mercy Killing!” February 25, 2000, reported on Islamonline.net.

⁹⁸⁰ Medical Fatawa dated 21 June 2006, *Can the State Intervene to Determine the Life of Individual?* World Fatwa Management and Research Institute Islamic University of Malaysia. <http://infad.usim.edu.my/> viewed on 4 February 2009.

⁹⁸¹ Purport of the Eighth Commission Decision, No.5, dated 3/7/1986 A.C.E., Concerning Resuscitation Equipment cited from Y. I. M. El-Shahat, ‘Islamic Viewpoint of Organ Transplantation’ (1999) 31 *Transplantation Proceedings*, 3271-3274, p. 3272

⁹⁸² El-Shahat, Y. I. M, ‘Islamic Viewpoint of Organ Transplantation’ (1999) 31 *Transplantation Proceedings*, 3271-3274, p. 3272

concept⁹⁸³. This shows the importance of having clear understandings and information on a certain issue before any judgements or opinions can be made. This is the reason why, in matters involving recent scientific and technological advances, many ulema have concluded that requiring specialist knowledge, for example, in medical practice, is preferable. So practically, the consensus group will include a broad and diverse representation of ulema and specialist clinicians from relevant disciplines to provide better background information on the particular issue⁹⁸⁴. The study also revealed that having knowledge about the condition of the organ, for example, from whom the organ was harvested, or organs harvested on the concept of spousal donation, including the timing of death, can be considered as influencing factors on local imams (community leaders) and the public at large ⁹⁸⁵.

In the United Kingdom, the Muslim Law Council, which consists of scholars from all major Muslim Schools of Law together with three distinguished lawyers, accepted this brain death concept based on the medical profession's definition, and considered brainstem death as the proper definition of death. So, once brainstem death is confirmed, it is treated as the end of life, thus allowing organ transplantation and donation to proceed⁹⁸⁶. This statement had been agreed by both Sunni and Shia scholars after two years of discussions⁹⁸⁷. However, there is still a requirement for consent to be obtained from the deceased him/herself during his/her lifetime or even for the next of kin to have given permission on the deceased's behalf⁹⁸⁸. The Council considered organ donation as an agreed means of alleviating pain and saving lives. So, for easy recognition, Muslim donors are encouraged to carry donor cards⁹⁸⁹.

⁹⁸³ Al-Mousawi, M, Hamed, T, and Al-Matouk, H, 'Views of Muslim Scholars on Organ Donation and Brain Death' (1997) 29 *Transplantation Proceedings*, 3217

⁹⁸⁴ Gatrad A R, and Sheikh, A, 'Medical Ethics and Islam: Principles and Practice' (2001) 84 *Arch. Dis. Child*, 72-75, p.73.

⁹⁸⁵ Seyed R. Mousavi Shahid Behesti, 'Ethical Considerations Related to Organ Transplantation and Islamic Law' (2006) 4 *International Journal of Surgery*, 91-93, p.92

⁹⁸⁶ 'The Muslim Law (Shariah) Council and Organ Transplants' (1996) 4 *Accident and Emergency Nursing*, 73-75, p.73.

⁹⁸⁷ 'UK Shariah Council Approves Organ Transplants', (1995) *The Lancet*. Vol.346 July 29

⁹⁸⁸ 'The Muslim Law (Shariah) Council and Organ Transplants' (1996) 4 *Accident and Emergency Nursing*, 73-75, p.73.

⁹⁸⁹ 'UK Shariah Council Approves Organ Transplants', (1995) *The Lancet*. Vol.346 July 29

Under Islamic law, too, it is essential for the brain death of a person to be verified by more than one physician⁹⁹⁰. However, Muslim Jurists are not prepared to accept patients in a vegetative state or anencephalics as being legally dead in the real sense⁹⁹¹. Frustratingly, in Egypt there are still many senior Muslim scholars who accept the fact that a brain-dead person is dying, but decline to accept that this person is actually already dead⁹⁹². This is one of the main reasons why Egypt has failed to establish cadaver organ donation programmes and is having difficulties in obtaining consent for donations. These minority Muslim scholars who reject the concept of brain death find the notion inappropriate⁹⁹³. In contrast, in other Islamic countries such as Kuwait, Iran and Saudi Arabia, where the concept of brain death is fully accepted, organ donation is encouraged, well-accepted and successfully developing. Saudi Arabia has even adapted the system of obtaining consent from the next of kin before organ retrieval in brain-dead patients and about half of all kidneys for transplantation are derived from cadavers, with the application of brain death criteria⁹⁹⁴.

From all the discussions above, similarly to the rulings on organ donation there are various views by different Muslim scholars on the interpretation of death. The reason for this diversity is the absence of a precise definition of death provided in the *Quran* or the *Sunnah* of the Prophet. *Allah* says to the effect:

*“Allah receives (men’s) soul at the time of their death, and that (soul) which dies not (yet) in its sleep. He keeps that (soul) for which He has ordained death and dismisses the rest till an appointed term”*⁹⁹⁵.

Many religious books refer to death as the departure of the soul from the body; unfortunately there is no further elaboration of the clear signs which signify this

⁹⁹⁰ Vanzan Paladin, A, ‘Ethics and Neurology in the Islamic World. Continuity and Change’ (1998) 19 *Ital J Neurol Sci*, 255-258. p.258.

⁹⁹¹ Albar MA, ‘Islamic Ethics of Organ Transplantation and Brain Death’ (1996) 7 *Saudi Kidney Dis. Transplant* 109

⁹⁹² Shaheen F.A.M, and Souqiyyyeh, M.Z, ‘Increasing Organ Donation Rates From Muslim Donors : Lessons From a Successful Model’ (2004) 36 *Transplantation Proceedings*, 1878-1880, p.1879

⁹⁹³ Gatrad A R, and Sheikh,A, ‘Medical Ethics and Islam: Principles and Practice’ (2001) 84 *Arch. Dis. Child*, 72-75, p.74.

⁹⁹⁴ Shaheen, FAM, Ramprasad ,KS, ‘Current Status of Organ Transplantation in Saudi Arabia’ ((1996) 28(3) *Transplantations Proceedings*, 1200-1.

⁹⁹⁵ Al-Quran. Surah Az-Zumar:42

‘departure’⁹⁹⁶. The fact that the soul is a mysterious thing and that nobody has been able to discover its nature makes its presence in the body noticeable as it results in life which could be observed by movement and other conventional signs⁹⁹⁷. Therefore, to this day, there is no single interpretation available of the concept of death that is consensually well-accepted by all Muslim countries⁹⁹⁸. This weakness might cause not only confusion but also suspicions among the Muslim public about the true concept of brain death, leaving them with a fear that they might be wrongly diagnosed⁹⁹⁹. Hence, there is a need for detailed explanations of these concepts to be fully exposed to influential Islamic scholars with assistance from experts in the medical profession. Hopefully, by providing sufficient understanding on these issues, Muslim scholars can collectively reach a single judgement on whether to accept this concept of brain death or not, consequently making it easier for the public to reach their own individual decisions or form views based on these scholars’ guidance and fatwas.

7.8 ISLAM AND ORGAN TRADING

Paid organ donation has been strongly disapproved of and condemned by several fatwas all over the Islamic world¹⁰⁰⁰. There is even an ethical consensus around the world that there should be no monetary compensation for transferable organs, either from living or deceased persons¹⁰⁰¹. Islam treats organ donation as an act of charity, benevolence and altruism as, by virtue of it, many precious lives have been saved. Islam does not allow human organs to be considered as commodities but enjoins them to be donated for the sake of love towards one’s fellow man and the spirit of brotherhood. Any act of commercializing organs or permitting organ-trafficking is considered to be against the

⁹⁹⁶ Al-Mousawi,M, Hamed,T, and .Al-Matouk,H, ‘Views of Muslim Scholars on Organ Donation and Brain Death’ (1997) 29 *Transplantation Proceedings* 3217

⁹⁹⁷ ‘The Muslim Law (Shariah) Council and Organ Transplants’ (1996) 4 *Accident and Emergency Nursing*, 73-75, p.73.

⁹⁹⁸ Abdallah S. Daar and Binsumeit Al Khitamy, A, ‘Bioethics for Clinicians: 21.Islamic Bioethics’ (2001) 164(1) *CMAJ* 60-63, p.62

⁹⁹⁹ Seyed R. Mousavi Shahid Behesti, ‘Ethical Considerations Related to Organ Transplantation and Islamic Law’ (2006) 4 *International Journal of Surgery*, 91-93, p.92

¹⁰⁰⁰ Abdel Moneim Hassaballah, ‘Definition of Death, Organ Donation and Interruption of Treatment in Islam’ (1996) 11 *Nephrol Dial Transplant* , 964-965. p.965.

¹⁰⁰¹ Seyed R. Mousavi Shahid Behesti, ‘Ethical Considerations Related to Organ Transplantation and Islamic Law’ (2006) 4 *International Journal of Surgery*, 91-93, p.91

principles of human dignity¹⁰⁰². Therefore it is not permissible and forbidden for Muslims¹⁰⁰³.

A fatwa confirming the prohibition of paid organ donation was passed at the 4th International Conference of Islamic Jurists held in Jeddah in 1988 and by the Grand Mufti in Egypt (1988). During the Third International Congress of the Middle East Society in 1992, Sheikh M.M.Sellami, the Grand Mufti of the Republic of Tunisia, reasoned that, according to Islam, a human being is not the owner of a part or the whole of his body. Therefore, there should be no cases where organs are traded, as the sale of bodily organs is categorically prohibited¹⁰⁰⁴. Instead, Islam promotes the act of donating organs¹⁰⁰⁵ and encourages altruism¹⁰⁰⁶. Paid organ donation was also condemned by the Jordanian Law no. 23 (1977) and no. 17 (1980), the Iraqi law no. 85 (1986), and the Saudi Centre for Organ Transplantation in 1993, on the basis that the body of the human being including its organs is not for sale¹⁰⁰⁷. They maintained that the selling of body organs is absolutely prohibited by Islam, as human bodies and their organs were never meant for sale and trading purposes. Shaykh Jad al Haq ‘Ali Jasd al Haq of al Azhar University, Cairo, Egypt, agrees that it is *haram* (forbidden) under the *Shariah* to sell human organs, as such a sale would violate the dignity and honour of man¹⁰⁰⁸.

¹⁰⁰² El-Shahat, Y. I. M, ‘Islamic Viewpoint of Organ Transplantation’ (1999) *31 Transplantation Proceedings*, 3271-3274, p. 3273.

¹⁰⁰³ Muzammil Siddiqi, Medical Fatawa dated 22 May 2006, *Organ Donation*, World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/> viewed on 4 February 2009.

¹⁰⁰⁴ Gatrad A R, and Sheikh, A, ‘Medical Ethics and Islam: Principles and Practice’ (2001) 84 *Arch. Dis. Child*, 72-75, p.75

¹⁰⁰⁵ Bruzzone, P, ‘Religious Aspects of Organ Transplantation’ (2008) 40 *Transplantation Proceedings*, 1064-1067, p.1066

¹⁰⁰⁶ Al-Mousawi, M, Hamed T, and Al-Matouk, H, ‘Views of Muslim Scholars on Organ Donation and Brain Death’ (1997) 29 *Transplantation Proceedings*, 3217

¹⁰⁰⁷ Abdel Moneim Hassaballah, ‘Definition of Death, Organ Donation and Interruption of Treatment in Islam’ (1996) 11 *Nephrol Dial Transplant*, 964-965, p.965.

¹⁰⁰⁸ Abul Fadl Mohsin Ebrahim, ‘Organ Transplantation: Contemporary Sunni Muslim Legal and Ethical Perspectives’ (1995) *Bioethics* Volume 9 Number 3/4, 291-302, p.297; and Muzammil Siddiqi, Medical Fatawa dated 22 May 2006, *Organ Donation*, World Fatwa Management and Research Institute, Islamic Science University of Malaysia. <http://infad.usim.edu.my/>. Viewed on 4 February 2009.

The Muslim Law (*Shariah*) Council in UK also resolved that organ donation must be given freely without rewards, and firmly ruled out organ-trading¹⁰⁰⁹. However, some suggestions for certain exceptions to this general rule were raised through a study conducted in six Islamic countries - Kuwait, Saudi Arabia, Iran, Egypt, Lebanon and Oman. Views were sought from thirty-two senior Islamic scholars on the issue of buying and selling organs¹⁰¹⁰. Collectively, all the scholars agreed that organ-trading is degrading and is not permissible. However, twenty-two scholars (68.7%) permitted the buying of an organ to save a patient's life especially when the donor insists on selling and when the patient has no alternative recourse. The fact that people have become very materialistic and it may not be possible to find a free organ nowadays makes it necessary to purchase the organs, but a Muslim must never sell his/her organs¹⁰¹¹.

Twenty-one scholars also permitted the donor to ask for a reward in return for his/her "donation"¹⁰¹². This issue has also been raised in other discussions where some argue that this reward is not meant to constitute a payment for the donated organs but is actually considered as compensation to cover the living donor's expenses for travelling, housing and loss of wages resulting from the deed of donation¹⁰¹³. Moreover, considering the fact that the 'altruistic system' alone cannot solve the organ shortage problem, even those from the transplant community believe that providing some financial incentives or social benefits to the individual or family of the donor is now necessary to increase the supply of cadaveric or living organs¹⁰¹⁴.

¹⁰⁰⁹ 'The Muslim Law (Shariah) Council and Organ Transplants' (1996) 4 *Accident and Emergency Nursing*, 73-75, p.73.

¹⁰¹⁰ Al-Mousawi, M, Hamed T and Al-Matouk, H, 'Views of Muslim Scholars on Organ Donation and Brain Death' (1997) 29 *Transplantation Proceedings*, 3217

¹⁰¹¹ Muzammil Siddiqi, Medical Fatawa dated 22 May 2006, *Organ Donation*, World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/> viewed on 4 February 2009.

¹⁰¹² Al-Mousawi, M, Hamed T, and Al-Matouk, H, 'Views of Muslim Scholars on Organ Donation and Brain Death' (1997) 29 *Transplantation Proceedings*, 3217

¹⁰¹³ Bruzzone, P, 'Religious Aspects of Organ Transplantation, (2008) 40 *Transplantation Proceedings*, 1064-1067, p.1065

¹⁰¹⁴ Seyed R. Mousavi Shahid Behesti, 'Ethical Considerations Related to Organ Transplantation and Islamic Law' (2006) 4 *International Journal of Surgery*, 91-93, p.91

Based on the current situation where it has become extremely difficult to obtain the needed organs and people have become very materialistic, some jurists suggest that, out of necessity, one can purchase the organs; however, a Muslim should never sell his/her organs to others¹⁰¹⁵. Although the general attitude in Islam considers organ donation to be an act of altruism, and there should not be any elements of organ-trading involved, the concept of gifting is treated as a different issue. A gift is permissible and may be given to the donor. However, it should not correspond to the hypothetical value of the organ given¹⁰¹⁶ and it must not be stipulated in discussions occurring before the organ donation takes place.

7.9 THE ISLAMIC PERSPECTIVE ON ORGAN DONATION IN MALAYSIA

In Malaysia in particular, the essence of religion is always given priority and recognition. Unlike in secular societies, religious values *do* have an impact on various healthcare issues¹⁰¹⁷. The majority of Malaysians are Muslims, which clearly justifies Islam being declared the main religion professed. The 1957 Federal Constitution under article 3 (1) states the following:

“Islam is the religion of the Federation; but other religions may be practised in peace and harmony in any part of the Federation.”

By virtue of the above article, the position of Islam is secured and treated as absolute because the Federal Constitution itself, which is the supreme law of Malaysia, guarantees this. As the main religion professed is Islam, it has become the religion of the federation, but at the same time recognition is still given to followers of other religions to practise their religion and rituals. Other religions which are also practised, including Buddhism, Hinduism and Christianity, are not prohibited nor abandoned. Adherents of religions other than Islam have equal rights to practise and profess their religious beliefs as long as it is done in peace and harmony. Personally, this reflects the beauty and uniqueness of

¹⁰¹⁵ Muzammil Siddiqi, Medical Fatawa dated 22 May 2006. *Organ Donation*, World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/> viewed on 4 February 2009

¹⁰¹⁶ Vanzan Paladin, A. ‘Ethics and Neurology in the Islamic World. Continuity and Change’ (1998) 19 *Ital J Neurol Sci*, 255-258, p.258.

¹⁰¹⁷ John D. Blum, Norchaya Talib, Pieter Carstens et al, ‘Rights of Patients: Comparative Perspectives from Five Countries’ (2003) 22 *Med & L*. 451

having a multiracial country that celebrates and respects its people's diversity and mainly comprises Malays, Chinese and Indians under the same roof.

Similarly to other Islamic countries, the Islamic perspective on organ donation issues has also been highlighted in Malaysia. Although the first kidney transplant only took place in Malaysia in 1975, there was already a fatwa released by the National Fatwa Council on 23rd June 1970, in its very first Fatwa Committee meeting. This initial fatwa allowed Muslims in Malaysia to undergo organ donation procedures¹⁰¹⁸. The fatwa addressed both living and cadaveric organ donations as long as certain conditions were fulfilled. This included not having elements of selling and bargaining involved, obtaining full consent and there being no other alternative treatment available to save the patient's life. Later, in 2005, another fatwa was released by the Malaysian National Fatawa Council on the application of tissue-grafting in medical practice¹⁰¹⁹. The council decided that it is permissible to use the tissue graft as long as it is only for medical purposes and that the tissue grafts must not be misused for other purposes such as business transactions. Additionally, the Council released a fatwa allowing organ donations involving eyes and hearts transplanted from a deceased donor to a living person. However, this procedure is only justifiable in extremely urgent circumstances, particularly where the life of the patient is depending on this transplant and such an operation will positively succeed.

The donor, too, must have been confirmed as dead before the beginning of such an operation. Necessary precautions must also be taken to avoid homicide and organ-trading from taking place¹⁰²⁰. Consent for the organ donation must be obtained from the donor him/herself in natural death cases but, alternatively, the deceased's family is allowed to give consent in fatal accident cases. A fatwa relating to blood donation was also released

¹⁰¹⁸ 'Fatwa Derma Organ'. Utusan Malaysia Online, 21st November 2006. http://www.utusan.com/utusan/acrchive.asp?y=2006&dt=1121&pub=utusan_mala viewed on 2nd.April 2007.

¹⁰¹⁹ Fatawa/ Malaysian National Fatawa Council dated 14 August 2005, *The Fatwa on the Application of the Tissue Graft in the Medical Practice*, World Fatwa Management and Research Institute Islamic Science University of Malaysia <http://infad.usim.edu.my/> viewed on 4 February 2009

¹⁰²⁰ Fatawa Malaysian National Fatawa Council dated 14 August 2005, *The Fatwa on the Application of the Tissue Graft in the Medical Practice*, World Fatwa Management and Research Institute Islamic Science University of Malaysia <http://infad.usim.edu.my/> viewed on 4 February 2009

in the same sitting, making it permissible to donate blood. The fatwa further explained that there is no need to separate the Muslim blood from the non-Muslim blood as both can be used and managed interchangeably. However, the fatwa did mention that it is not encouraged to give money to the blood donor even for the purpose of showing gratitude¹⁰²¹. By virtue of all these fatwas, there should be no doubts existing among Muslim Malaysians on the permissibility of being involved in any organ donation procedures.

7.10 BRAIN-DEAD PATIENTS INVOLVED IN ROAD TRAFFIC ACCIDENTS AS A SOURCE OF CADAVERIC DONORS

When organs are to be taken from donors, either living or cadaveric, both situations require consent to be obtained first. For living donors, it is clear that they themselves must decide and provide consent but, for cadaveric donations, if there is no express wish made known, alternatively the authority to decide will be extended to the relatives of the deceased. However, could it be possible to extend this authority to the state, especially in situations of extreme urgency? Serious consideration must be given to factors such as the scarcity of human organs available, the urgent need of the dying patient and also the time factor, when organs might deteriorate but the relatives of the deceased cannot be contacted for their consent. Any unnecessary delay would obviously result in such precious organs being wasted as these organs can only be preserved for a short period of time outside a living body. This scenario frequently occurs, especially in accident and emergency units at hospitals where plenty of severe accident cases are brought in daily. The issue is, would Islam consider allowing patients who have suffered brain death resulting from accidents to be considered as potential organ donors without obtaining any consent from the deceased during his/her lifetime or from his/her relatives afterwards?

Arguing on the evidence derived from primary sources of Islam, including the Quran, Sunnah and Ijma', there is no doubt that organ donation is permissible for Muslims. But to utilize organs from brain-dead accident victims without first obtaining consent, perhaps one could rely on the legal maxim mentioned earlier: "necessities render the

¹⁰²¹ *Ibid*

prohibited lawful”. Arguing on the basis that supply of human organs is now very critical and scarce, perhaps we could re-use organs from these accident victims.

Even during the First International Conference on Islamic Medicine it was agreed that the donation of body parts could be considered a social obligation. Under the Islamic Law, this will be termed as *fard kifaya*, which means that it is a collective duty and it must be fulfilled by a sufficient number of community members though not necessarily by all. So, the community is under a collective obligation to find the necessary organs for organ donation, to preserve the precious lives and health of its sick members. Here, the medical staffs in charge of transplantation matters represent the community as a whole¹⁰²². So, the requirement that medical staff are obliged to obtain permission of the deceased or his relatives for any organ removal in cadaver donations is not applicable in each and every case¹⁰²³.

Sheikh Tantawi said that it was still necessary to seek permission from the inheritors but, in cases where none are available, permission must be sought from the appropriate legal authority. However, seeking such permission is not a binding condition on these medical staff, especially when they believe that the need for the organ is extremely urgent to save other patients’ lives¹⁰²⁴. In this situation too, the “lesser evil” principle is also relevantly applicable as saving precious lives is more urgent than the deceased’s wishes since he/she is already dead and cannot benefit from or be harmed by the procedure¹⁰²⁵. This contention is again supported by another maxim: “the most harmful detriment is removable by the less harmful one”.

The Fiqh Academy of the Organisation of the Islamic Conference in Jeddah, during the Islamic year 1408, and the Mufti of Egypt, Dr. Sheikh At-Tantawi, allowed and approved the use of the body organs of a person who has died in an accident if the necessity requires the use of any organ to cure a patient, provided that a competent and trustworthy

¹⁰²² Islamic Code of Medical Ethics. Kuwait. January 1981. p.81

¹⁰²³ *Ibid*

¹⁰²⁴ Sahin Aksoy, ‘ A Critical Approach To The Current Understanding of Islamic Scholars on Using Cadaver Organs Without Prior Permission’ (2001) *Bioethics*, Volume 15 Number 5/6, p.471

¹⁰²⁵ *Ibid*

Muslim physician makes this decision¹⁰²⁶. Another Islamic scholar, at the Islamic Institute of Toronto, Ontario, Canada, Sheikh Ahmad Kutty, in his Fatwa stated that organs can be harvested from victims of traffic accidents if their identities are unknown. However, before this can be done, a valid decree of a judge must first be obtained¹⁰²⁷. These fatwas by prominent Islamic scholars offer some hope that it will be permissible to harvest organs from accident cases. Although it is still preferable to get the needed consent, there is still room for exceptions in certain situations where medical physicians and the court might be regarded as the alternative consenting authority.

7.11 THE LIVING WILL (WASIYYAH)

Muslims are ordained and urged to prepare wills as this is enjoined by the teachings of Islam. A will under the Islamic Law could include specific stipulations such as matters relating to the management of young children, arranging marriage of the testator's daughters and devolution of one third of the testator's estate in favour of certain individuals or charitable organisations¹⁰²⁸. Allah clearly states in the Quran:

*“O you who believe! When death approaches any of you, (take) witnesses among yourselves when making bequests, two just men of your own brotherhood or others from outside if you are journeying...”*¹⁰²⁹

The Prophet was also reported to say:

*“It is not right for any Muslim person, who has anything to bequeath, that he may pass even two nights without having his last will and testament written and kept ready with him”*¹⁰³⁰.

Nowadays, due to rapid changes and interventions by the government and courts, it is even more crucial to prepare Islamic wills that not only cater for the distribution of inheritance but also provide instructions related to our medical treatments and having a

¹⁰²⁶ Muzammil Siddiqi. Medical Fatawa dated 22 May 2006, *Organ Donation*, World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/> viewed on 4 February 2009

¹⁰²⁷ Medical Fatawa dated 16 June 2006, *Islam's View on Organ Transplants and Donations*, World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/>, viewed on 4 February 2009

¹⁰²⁸ Abul Fadl Mohsin Ebrahim, 'Organ Transplantation: Contemporary Sunni Muslim Legal and Ethical Perspectives' (1995) *Bioethics* Volume 9 Number 3/4, 291-302, p.300

¹⁰²⁹ Al-Quran. Surah Al Maidah: 106

¹⁰³⁰ Al-Bukhari, Muhammad bin Ismail. Sahih al Bukhari. Cairo: Dar al Sha'b, "Kitab Wasaya". Vol 4, p.2

proper Islamic burial¹⁰³¹. Preparing an ordinary will is necessary as death is an inevitable phenomenon and can occur anytime, anywhere and to anyone. This type of will is usually read and adhered to after the testator has died; however, a living will will start to take effect even while the patient is still alive but is unable to give further instructions on his/her treatments if he/she is a victim of a terminal illness, has lapsed into irreversible coma or is already in a persistent vegetative state (PVS),¹⁰³² which prevents him/her from doing so. In other words, a living will, also known as Advance Medical Directives, is a document safeguarding our right to die and further explaining what we would wish for.

The living will is also a document in which a healthy person explains in writing which medical treatment he/she would accept or refuse at that critical juncture when he/she may not be in a position to express his/her wishes as a result of serious illness or injury. So, this document assists the attending physician to withhold or withdraw certain medical procedures and allow the patient to die naturally¹⁰³³. However, although a majority of Muslim jurists approve of living and cadaver organ donation, the issue of whether one is permitted to include one's organ donation wishes and instructions in a will is a different issue altogether. Again, as there are no clear-cut, direct answers found within the primary sources of law, *ijtihad* is thus the best tool to use for a solution.

The Islamic Fiqh Academy of India in 1989 disapproved of this and considered that these requests should not be treated as an enforceable will according to the *Shariah*. Their arguments are that human organs are gifted to humans by their Creator so they have no right whatsoever to further pass them on to another person. Moreover, since humans are invaluable, we cannot make a gift in respect of them and set a price on them¹⁰³⁴. However, there is another view that approves the practice of promoting living wills. For example, the Council of the Islamic Fiqh Academy of the Muslim League, in Makkah,

¹⁰³¹ Medical Fatawa dated 21 June 2006, *Who Takes A Patient's Life?* World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/> viewed on 4 February 2009

¹⁰³² Abul Fadl Mohsin Ebrahim, 'The Living Will (Wasiyat Al Hayy): A Study of its Legality in the Light of Islamic Jurisprudence' (2000) 19 *MEDLAW* 147

¹⁰³³ *Ibid*

¹⁰³⁴ Abul Fadl Mohsin Ebrahim, 'Organ Transplantation: Contemporary Sunni Muslim Legal and Ethical Perspectives' (1995) *Bioethics* Volume 9 Number 3/4, 291-302, p.300

Saudi Arabia, in 1985 ruled that this type of will is permissible in *Shariah* and this includes allowing cadaver organs to be transferred to living recipients as long as it is ensured that the donor was a sane person when making the decision and that he/she had really wanted the donation to take place after his/her death¹⁰³⁵. This was then further supported by the Islamic Fiqh Academy of the Organisation of Islamic Conference (OIC) in 1988; this allowed the practice, as long as the transplant was really necessary to keep the beneficiary alive and well, and provided that the deceased, or his/her heirs, or even the concerned authorities had authorized it¹⁰³⁶. Their positive assertions relied on the concepts of necessity, altruism and generosity towards mankind.

Although there is still no exact view supported as a whole by all Muslim jurists, there is an urgent need for uniformity, as the number of organs harvested is becoming very scarce. According to Dr. Muzammil Siddiqi, president of the Fiqh Council of North America, having an Islamic will is advisable not only for the distribution of inheritance but also for clarifying and authorising our medical treatment in coma cases and other severe medical complications, including for a proper Islamic burial¹⁰³⁷. However, some take the view that the last will and the living will should be two different documents. This is because the *Al-Wasiyah*, which is an Arabic word equivalent to the last will, is only executed after death takes place¹⁰³⁸. This contradicts the purpose of having a living will, which normally deals with providing instructions on the management and wishes of the person when he/she is no longer able to do so.

It is significant also to note that, in a living will of a Muslim, one cannot ask for death, as euthanasia is not permissible; it is considered equivalent to suicide and is a crime under Islamic law. Additionally, as cadaveric organ donation is permissible in Islam, there are considerations to include organ donation in a Muslim's living will. This is based on the concept of *al-maslahah*, where the wellbeing and general welfare of others are given

¹⁰³⁵ *Ibid*, p.301

¹⁰³⁶ *Ibid*

¹⁰³⁷ Medical Fatawa dated 21 June 2006, *Who Takes a Patient's Life?* World Fatwa Management and Research Institute Islamic Science University of Malaysia. <http://infad.usim.edu.my/> viewed on 4 February 2009.

¹⁰³⁸ Abul Fadl Mohsin Ebrahim, 'The Living Will (Wasiyat Al Hayy): A Study of its Legality in the Light of Islamic Jurisprudence' (2000) 19 *MEDLAW* 147

priority, and on the concept of altruism that promotes kindness and generosity towards mankind¹⁰³⁹. In practical terms, it would be necessary for a Muslim living will to entrust someone with the power of attorney, and this person's name must be mentioned in this living will¹⁰⁴⁰ for recognition and authority purposes. This document must also be signed by the person making the living will and two valid witnesses¹⁰⁴¹. So, according to Abul Fadl, a Muslim may draw up an alternative living will to include in it instructions pertaining to cessation of treatment, switching off the life support machine, and organ donation. However, none of the clauses of the living will should contradict the teachings of Islam¹⁰⁴². The researcher positively supports the idea of encouraging people to include organ donation instructions in their wills, as it could ensure harvesting of their organs for those in need, while also providing comfort to the family members, as they need not try to guess the real wishes of the deceased, something in which they are, indeed, likely to err. If these confusions, which are causing dilemmas to the public in making their judgement, can be resolved, in the near future we might obtain even more potential organs that could save thousands more lives.

CONCLUSION

Organ donation is clearly accepted and permissible in Islam. Islamic teachings and fatwas allow such practice, so all Muslims should take advantage of this technology and clear up existing confusion related to its permissibility. Undoubtedly, confusions in religious stances have a negative impact, particularly in the development of transplantation programs in Muslim countries¹⁰⁴³. Now, however, there is gradual acceptance in the Muslim world of recognizing organ donation as the alternative treatment for end-stage organ failure. Nonetheless, to further promote organ donation among Muslims, it is paramount to urge Islamic scholars to discuss the matter and derive a single conclusion,

¹⁰³⁹ *Ibid*

¹⁰⁴⁰ *Ibid*

¹⁰⁴¹ The requirement for having two witnesses is based on the Al- Quran, Surah Al Baqarah: 282 which says to the effect: "...and get two witnesses out of your own men..."

¹⁰⁴² Abul Fadl Mohsin Ebrahim, 'The Living Will (Wasiyat Al Hayy): A Study of its Legality in the Light of Islamic Jurisprudence' (2000) 19 *MEDLAW* 147

¹⁰⁴³ Al-Mousawi, M, Hamed, T, and Al-Matouk, H, 'Views of Muslim Scholars on Organ Donation and Brain Death' (1997) 29 *Transplantation Proceedings*, 3217

thus further clearing up any existing confusion. Once all these concepts are apparent and uniform, this religious aspect of permission must be stressed and relevant fatwas must be cited to the relatives of the deceased¹⁰⁴⁴, to provide them with understanding and clarity, which will hopefully assist them in making a positive decision to allow organ donations.

Support from religious authorities is absolutely crucial to help decrease the refusal rate¹⁰⁴⁵. Views held by these influential religious people are considered very important because their opinions will surely guide public attitudes and behaviour¹⁰⁴⁶. People with strong religious or spiritual objections to organ donation often change their stand when they realize that respected religious leaders have issued statements supporting organ donation¹⁰⁴⁷. In other words, religious officers must work hand in hand with the medical community to disseminate these contemporary rulings¹⁰⁴⁸, while the Muslim doctors, too, must take up the challenge to act as mediators between the medical and religious spheres¹⁰⁴⁹. This collaboration will then allow Medicine and Law in the Muslim world to be perfect and comprehensive, as the physicians will give rules to preserve the physical body while the jurists will preserve the health of the social body¹⁰⁵⁰.

¹⁰⁴⁴ Al-Khader A.A.,and Shaheen, F, 'Strategies for Increasing Transplantation: the Saudi Experience' (1991) 31 *Transplantation Proceedings*, 3278

¹⁰⁴⁵ .Al-Mousawi, M.Samhan, M, .Al-Mezairee, I, Razzak M.A and. Khawari, F 'Cadaver Organ Procurement in Kuwait' (1999) 31 *Transplantation Proceedings*, 3375-3376

¹⁰⁴⁶ .Kecucioglu, N, Tuncer,M, Yucetin, L.. Akaydin, M and Yakupoglu, G. 'Attitudes of Religious People in Turkey Regarding Organ Donation and Transplantation' (2000) 32 *Transplantation Proceedings*, 629-630, p.629

¹⁰⁴⁷ Susan E. Morgan, Micheal T. Stephenson, Tyler R. Harrison, Walid A. Afifi and Shawn D. Long, 'Facts Versus 'Feelings': How Rational Is The Decision To Become An Organ Donor?' (2008) 13(5) *J. Health Psychol*, 644-658. p.655

¹⁰⁴⁸ Abdallah S. Daar and A.Binsumeit Al Khitamy, 'Bioethics for Clinicians: 21. Islamic Bioethics' (2001) 164(1) *CMAJ*, 60-63, p.62

¹⁰⁴⁹ Vanzan Paladin, A, 'Ethics and Neurology in the Islamic World. Continuity and Change' (1998) 19 *Ital J Neurol Sci* , 255-258, p.256

¹⁰⁵⁰ Vanzan Paladin, A. 'Ethics and Neurology in the Islamic World. Continuity and Change' (1998) 19 *Ital J Neurol Sci*, 255-258. p.256.

CHAPTER 8

TOWARDS A BETTER ORGAN DONATION SYSTEM IN MALAYSIA

INTRODUCTION

Organ shortage in Malaysia is not primarily the result of a lack of suitable donors but, rather, the result of failure to identify organ donors, failure to obtain consent and procure organs and, worst of all, objections and refusals from the deceased's family preventing the donation from proceeding. Therefore there is a need to implement a more aggressive and systematic organ donation management system, which might increase the number of registered potential donors, as well as actual donors, while removing any barriers hindering organ donation from taking place. Every solution employed must be exercised with careful planning, prioritizing and co-ordination, together with strong teamwork and a high sense of responsibility. Malaysia, as a multiracial, multi-faith country, must also consider its social, economic, religious, cultural and ethical environment to ensure that any alternative adopted is positively applied and well-accepted by its people. Thus, this chapter will discuss potential suggestions to solve organ shortage problems in Malaysia.

8.1 MAINTAINING THE OPTING-IN SYSTEM

First and foremost, the researcher believes that the organ shortage problems in Malaysia are not caused by the opting-in system. Therefore, there is no need to change to the opting-out system suggested¹⁰⁵¹. Moreover, the opting-out system itself does not ensure higher rates of donations compared to the opting-in system¹⁰⁵²; hence, it is not always the

¹⁰⁵¹ Puteri Nemie Jahn Kassim, 'Organ Transplantation in Malaysia: A Need for a Comprehensive Legal Regime', *Medicine & Law*, Vol.24, p.173.

¹⁰⁵² Coppen R, Friele RD, Marquet RL and Gevers SKM, 'Opting-Out Systems :No Guarantee for Higher Donation Rates', (2005) 18 *Transpl Int*, 1275-1279

ultimate solution for organ shortage problems¹⁰⁵³. However, by maintaining the opting-in system, we can ensure that patients and individuals retain their rights on human autonomy and make their own preferred decision based on their voluntary will and understanding of the issue. By respecting the known wishes of the patient, the integrity of the doctor-patient-public relationship will not be jeopardized, ensuring that trust and confidence are strongly maintained within the system itself¹⁰⁵⁴. These elements are absolutely essential, especially in creating an atmosphere where the public can feel safe, protected and respected, particularly in Malaysia, where organ donation issues are not completely well-accepted by the public. Simultaneously, elements of consent remain preserved and treated as a top priority, as the opting-in system does not compromise the requirement of consent from the donor himself, or at least from his next of kin, before any organ procurement procedure takes place. Consent must also be voluntary and not simply presumed. Therefore, maintaining a lenient system such as opting-in could actually help produce a more positive attitude towards organ donation.

Active efforts taken by the Ministry of Health, Malaysia, in recruiting more registered organ donors is very much appreciated; however, unless drastic measures are taken to ensure these registered donors do become actual donors, there will not be any significant improvement in the organ shortage problem. For instance, the total number of registered organ donors with the National Transplant Registry from 1997 until May 2009 reached an inspiring total of 128,556 people¹⁰⁵⁵, where 57% are Chinese, 23.4% are Indians, 14 % are Malays and the remaining 5.6 % are represented by other races. The latest statistics, from January 2011 to May 2011, record an additional 15,839 potential donors registering, but only 18 actual donations taking place¹⁰⁵⁶. The steady increase in the number of potential donors registering each year is indeed something to be proud of, but the organ shortage problem will remain unless barriers preventing registered organ donors from proceeding to become actual donors are removed. This weakness is clearly demonstrated

¹⁰⁵³ Linda Wright, 'Is Presumed Consent the Answer to Organ Shortage? No', (2007) *BMJ*, 334:1089 (26 May)

¹⁰⁵⁴ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 8.2, p.17

¹⁰⁵⁵ Rabiatul Adawiyah Koh Abdullah, 'Menyelamatkan Nyawa Penerima Organ', Utusan Online, 26 July 2009, <http://www.utusan.com>. Viewed on 26 July 2009.

¹⁰⁵⁶ National Resource Transplant Centre, www.agiftoflife.gov.my, viewed on 30 June 2011

by statistics showing that, from 1976 until 31 May 2011, a total of only 327 actual donations have taken place¹⁰⁵⁷. This suggests that the opting-in system does work well, as statistics evidently show a steady increase in the numbers of registered potential organ donors every year; however, something is preventing these organ donors from becoming actual donors later. So, the increasing number of registered organ donors is meaningless if the strong factors that are holding down the actual donation rate persist and are not dealt with effectively.

Sheehy et al.¹⁰⁵⁸ have argued that the organ shortage will not be solved even if all potential deceased donors do become actual deceased donors; however, this finding must not stop us from initiating further improvements. Perhaps it will not resolve the organ shortage totally, but at least fresh initiatives will definitely shorten the long waiting list of patients queuing for organs and, most important of all, plenty more organs will become available, subsequently allowing more precious lives to be saved. Therefore, the researcher would like to emphasize that it is as significant to identify factors preventing registered organ donors from becoming actual organ donors as it is to simply focus on the reasons why they are reluctant to come forward and register as donors. Once these factors are overcome, there will definitely be a momentous, positive rise in the number of actual organs finally procured. For that reason too, it would be a hasty decision for Malaysia to simply change to the opting-out system without first maximizing potential under the existing opting-in system. However, after some time, when the opting-in system has been exhaustively tried and it is then felt that a change in the procurement system is still necessary, comprehensive preliminary research to foresee its implications and the public's acceptance of the new suggestion must be initiated first before any changes take place.

Taking the example of the UK, it had taken the authorities several years of discussion and research to finally decide on this particular issue alone. In the beginning, a special taskforce was initially set up in 2006 to discuss various views and perspectives on the

¹⁰⁵⁷ *Ibid*

¹⁰⁵⁸ Sheehy E, Conrad SL, Brigham LE, et al, 'Estimating the Number of Potential Organ Donors in the United States, (2003) 349 *N. Engl J Med*, 667-674.

matter before the decision was reached to retain the existing opting-in system, at least for the next five years, and that the issue of considering opting-out should only be revisited should they fail to increase their organ donation rates by at least 50% by the year 2013¹⁰⁵⁹. Moreover, as John Forsythe, Chairman of the Scottish Transplant Group and transplant surgeon at the Royal Infirmary of Edinburgh says, “Legislation change is not that important, it is much more important that we get the structure around organ donation right”¹⁰⁶⁰. So, even if we change the legislation, but still allow the next of kin to refuse permission for organ retrieval, there still would be no guarantee that the number of organs retrieved would increase¹⁰⁶¹.

8.2 ELIMINATING FAMILY REFUSAL AND INFLUENCE

The fact that organ donation occurs at a time of tremendous stress and grief for families, as they struggle to accept the deep loss, initiates different responses. The families demonstrate their respect and bereavement through rituals and by proper disposal of the deceased’s body in funerals and burials¹⁰⁶². These are the feelings that cause many families to withhold consent for organ donation, as no-one would wish to exacerbate their grief by initiating procedures that “mutilate” their loved one’s body¹⁰⁶³. On the other hand, as familial consent is vital¹⁰⁶⁴, it is not advisable to totally set it aside. Doing so would be considered “ghoulish”, show lack of respect to the grieving family, and would reduce the already limited number of organ donors as well¹⁰⁶⁵. Similarly, the main factor

¹⁰⁵⁹ Elisabeth Buggins, Introduction by the Chair of the Organ Donation Taskforce, The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, p.3

¹⁰⁶⁰ Quoted from Emma Wilkinson, ‘UK Government Plans Shake-Up of Organ Donation Services’, (2008) *The Lancet*, vol.371, January 26, www.thelancet.com

¹⁰⁶¹ Eike-Henner Kluge, ‘Decisions About Organ Donation Should Rest With Potential Donors, Not Next of Kin’, (1997) 157 *Can Med Assoc*, 160-160, p.160

¹⁰⁶² Thomas May, Mark P. Aulisio and Michael A. DeVita, ‘Patients, Families, and Organ Donation: Who Should Decide?’, (2000) *The Milbank Quarterly*, Vol.78, No.2, 323-336, p.325

¹⁰⁶³ *Ibid*

¹⁰⁶⁴ Klassen, AC and D.K. Klassen, ‘Who Are the Donors in Organ Donation? The Family’s Perspective in Mandated Choice’, (1996) 125 *Annals of Internal Medicine*, 70-73

¹⁰⁶⁵ Thomas May, Mark P. Aulisio and Michael A. DeVita, ‘Patients, Families, and Organ Donation: Who Should Decide?’, (2000) *The Milbank Quarterly*, Vol.78, No.2, 323-336, p.328

causing the small number of actual donors in Malaysia is family rejection¹⁰⁶⁶. Each year, many donation opportunities from potential candidates are missed because of lack of familial consent¹⁰⁶⁷ which very much relates to their misunderstanding and acceptance of the brain death concept, fear of unequal access to transplantation and, of course, misconceptions of religious opinions¹⁰⁶⁸. Some other potential donors are lost to secondary haemodynamic collapse and subsequent cardiopulmonary arrest¹⁰⁶⁹, including cases where it is the donor's condition itself that is deemed medically unsuitable due to age factor, baseline medical status, including hepatitis and human immunodeficiency virus status, and the presence of malignancy¹⁰⁷⁰. In contrast to the two latter reasons, which are unavoidable and beyond the power of humans to arrest, family rejection is, on the other hand, something that can possibly be changed and avoided. Lee Lam Thye, chairman of the Health Ministry's Public Education Subcommittee on Organ Donation, Malaysia, concurred with the fact that, although there is an overwhelming response from the public in Malaysia to become organ donors, in reality there are very few actual donors because, when the hospital authorities approach the family of the pledger, they refuse and accuse the doctors and nurses of being heartless at their time of mourning¹⁰⁷¹. Consequently, a lot of potential organ donation opportunities continue to be lost year after year and drastic changes must be taken to prevent this situation from continuing.

Family rejection can interfere in two separate situations. Firstly, it can take place as early as before the individual registers as an organ donor, consequently stopping the individual from pursuing his/her intention to register; the other is when it hinders an existing

¹⁰⁶⁶ Rabiatal Adawiyah Koh Abdullah, 'Menyelamatkan Nyawa Penerima Organ', Utusan Online, 26 July 2009, <http://www.utusan.com>. viewed on 26 July 2009.

¹⁰⁶⁷ Ashley Britton Christmas, Eric J. Mallico, Gary W. Burris, RN Tyson A, Bogart, RN, Harry James Norton and Ronald F. Sing, 'A Paradigm Shift in the Approach to Families for Organ Donation: Honoring Patients' Wishes Versus Request for Permission in Patients With Department of Motor Vehicles Donor Designations', (2008) Volume 65, Number 5, *The Journal of TRAUMA, Injury, Infection, and Critical Care*, 1507-1510.

¹⁰⁶⁸ Szmidt, J, Kalicinski, P, Zakowski, J, Jonas, A, Waleski, P, and Zagorski, S 'Transplantation of Organs: Limitations and Possible Solutions', (2003) 35 *Transplantation Proceedings*, 1165.

¹⁰⁶⁹ Ali Salim, George C. Velmahos, Carlos Brown, Howard Belzberg and Demetrios Demetriades, 'Aggressive Organ Donor Management Significantly Increases the Number of Organs Available for Transplantation', (2005) Volume 58, Number 5, *The Journal of TRAUMA Injury, Infection, and Critical Care*, 991-994.

¹⁰⁷⁰ *Ibid*

¹⁰⁷¹ Annie Freeda Cruz, 'Saving Lives, One Pledge at a Time', Malaysian Society of Transplantation, <http://www.mst.org.my/news/090209nst.html>, Viewed on 28 August 2009.

registered organ donor in becoming an actual organ donor. This takes place when the deceased dies with known intentions of becoming an organ donor but, out of respect for the grieving family, their consent is sought before the actual organ procurement procedures are carried out. Any denial or objections expressed by the deceased's family can consequently prevent organ donation procedures from proceeding as hoped for¹⁰⁷². Moreover, in Malaysia, as discussed in chapter three, family rejection is considered valid and authoritative. This is the exact situation where potential organ donors, who are suitable to become organ donors, have their wishes overridden by their families. Therefore, action taken must be tailored to prevent families from using their conclusive authority to reject and oppose organ donation by their loved ones, as approximately half of the families of potential donors do refuse consent¹⁰⁷³.

One of the most effective ways to achieve this is to legally amend the Human Tissues Act 1974, particularly by removing the section contained therein which permits such occurrence to take place. So, section 2(2) (b) of the Act, which clearly acknowledges family objections particularly from the deceased's spouse and next of kin, must be removed. Hopefully, by implementing this change, we will be able to see more actual organ donations taking place as intended.

Likewise, the current law in Canada treats organ donation as a matter of altruism and it is left to the discretion of the individual to decide whether to become an organ donor or not. This practice, which upholds the principle of human autonomy, is clearly stated in the Human Tissue Gifts Act 1982 (or equivalent) of the various Provinces and Territories: the consent of a competent person is "full" and "binding" authority for the removal of that person's organs for transplantation purposes. Legally, it is understood from the word "full" that, if someone has given consent for the removal of his/her organs, then that consent itself is already sufficient and no-one else needs to be asked for further consent

¹⁰⁷² Thomas May, Mark P. Aulisio and Michael A. DeVita, 'Patients, Families, and Organ Donation: Who Should Decide?', (2000) *The Milbank Quarterly*, Vol.78, No.2, 323-336, p.323

¹⁰⁷³ Mark L. Robbins, Deborah A. Levesque, Colleen A. Redding et al, 'Assessing Family Members' Motivational Readiness and Decision Making For Consenting To Cadaveric Organ Donation', (2001) 6 *J Health Psychol*, 523-535, p.524

and permission¹⁰⁷⁴. The term “binding” means that no-one else may overrule the donor’s consent and later substitute it with his or her own wishes. However, in practice, the organ retrieval protocols of the various Canadian Transplant Societies do conflictingly state in their retrieval protocols that the consent of the next of kin is required for organ retrieval even in the presence of a valid donor organ bequest. It is also further stated that, if the next of kin refuses to allow the donation, then the particular organs will not be retrieved¹⁰⁷⁵. For instance, the Guidelines for Organ and Tissue Donation of the Multi Organ Retrieval and Exchange (M.O.R.E) Programme of Ontario states that

“A signed driver’s license/donor card is considered a legal document, but, it is the practice of the transplant programs to follow the wishes of the next of kin. If the next of kin refuse consent for organ and/or tissue donation their wishes must be respected”

These protocols clearly violate the actual intention of the law and are also in conflict with the principles of autonomy and altruism promoted by the legislation. Consequently, this application will frustrate people and undermine their confidence in the system, especially if one really intends to become an organ donor.

In the context of Malaysia, where family ties are often strong and essential in every family institution, it appears harsh to totally put aside family influence especially when it involves end-of-life issues, particularly organ donation. It is common for people to consult and involve their families in matters that affect the whole family. For example, in deciding a suitable date to solemnize a marriage, fixing marriage receptions, hosting familial functions and, most obviously, during religious celebrations, it is almost essential for everybody to get together and celebrate with their respective families. In such cases, everybody normally leaves for their hometown to be with their parents, siblings and relatives. Even in hard and depressing times, such as during illnesses and death, family members again unite to give support to one another. So, in the researcher’s opinion, if we were to totally set aside the family role and its influence in such a big issue as organ donation, this would presumably result in more unpopular consequences and perhaps

¹⁰⁷⁴ Eike-Henner W. Kluge, ‘Improving Organ Retrieval Rates : Various Proposals and Their Ethical Validity’, (2000) 8 *Health Care Analysis*, 279-295, p.289

¹⁰⁷⁵ *Ibid*

provoke even more rejections from the general public, particularly the bereaved families. Therefore, any alternative suggestion must be able to protect one's right to human autonomy and at the same time respect the role and influence of the family as well.

It is no longer sufficient to merely hope that families will be able to honour the deceased's wishes and that they will at least act in accord with the deceased's wishes to become an actual organ donor¹⁰⁷⁶. So, to strike a balance, while continuing to be sensitive to both parties, we must find a solution that respects the registered organ donor's wish while still involving and treating family members as important throughout the whole decision-making process. This could possibly be done by making some practical changes to the organ donation registration procedure itself. Therefore, it is advised that, when completing organ registration forms, not only should the individual alone pledge his/her wishes to donate organs but there should also be two witnesses supporting the potential organ donor's intentions. These two witnesses should preferably be close family members, for instance, parents, spouse, children, siblings or any other family members. Adding this requirement will indirectly allow the individual to confide in his/her family and discuss with them organ donation issues at an earlier stage, and he/she will be able to express his/her wish to become an organ donor.

Many states in the United States have already required potential organ donors to indicate their commitment by signing an organ donor card in the presence of two witnesses¹⁰⁷⁷. However, as advance directives are now becoming more popular, a few states have recently taken action to reduce or eliminate the witness requirement¹⁰⁷⁸. Nevertheless, the researcher believes that introducing this witness requirement to Malaysia would work out better than advance directives, which are a totally new concept. Fortunately, Malaysians are used to having the witness requirement as it is mandatory in other matters as well, such as solemnizing marriages. Moreover, reports from the UK Organ Donation Taskforce also clearly emphasize the importance of encouraging people to broach and

¹⁰⁷⁶ Barbera J. Daly, 'End-of Life Decision Making, Organ Donation, and Critical Care Nurses', (2006) 26 *Criti Care Nurse*, 78-86, p.80

¹⁰⁷⁷ Amitai Etzioni, 'Organ Donation : A Communitarian Approach', (2003) *Kennedy Institute of Ethics Journal*, Vol.13, No.1, 1-18, p12

¹⁰⁷⁸ *Ibid*

discuss organ donation issues, especially with families, friends and those closest to them, in order to help the NHS carry out its work more effectively¹⁰⁷⁹. So, the witness requirement does clearly promote this objective.

Recently, the Welsh Assembly Government sponsored an organ donation awareness campaign called 'Donate Wales: Tell a Loved One' to encourage people to discuss organ donation intentions with loved ones first before registering as organ donors¹⁰⁸⁰. Moreover, according to the European Union Committee, there is evidence that members of families who have discussed organ donation matters among themselves tend to be more likely to be willing to donate organs too¹⁰⁸¹. Despite family consent remaining the most important factor for a successful organ donation, studies have shown that less than half of those who have signed a donor card have discussed their intent with their families^{1082,1083}. Within the registered organ donor group analyzed in this study, it was found that not all of them had informed their families about their decision to become an organ donor. The results showed that, although 85% did inform their families, the remaining 15% chose to keep their decision to themselves, which is still a high percentage. Within this group, only 60% received support from their family while the remaining 40% had to face family objections to their decision to donate organs. This is again a high percentage and its consequences must be taken seriously as family objection is acknowledged by the law in Malaysia. One can imagine how many more organs will subsequently be wasted due to family rejection if nothing is done urgently to prevent it.

Making family witnesses an additional requirement will also help lift the burden from family members in deciding about donation, following a very sudden, unexpected and

¹⁰⁷⁹ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 1.16, p.5.

¹⁰⁸⁰ *Ibid*, para 14.7, p.32

¹⁰⁸¹ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 37, p.12.

¹⁰⁸² Morgan SE, Harrison TR, Long SD, Afifi W A, Stephenson MT, Reichert T, 'Family Discussions About Organ Donation: How The Media Influences Opinions About Donation Decisions', (2005) 19 *Clin Transplant*, pp. 674-682.

¹⁰⁸³ Siminoff L, Gordon N, Hewlett J, Arnold RM, 'Factors Influencing Families Consent for Donation of Solid Organs in Transplantation', (2001) 1 *JAMA*, pp.71-77.

untimely death, which is undeniably a situation of great distress and grief. As such, the emotional environment is significantly reduced when organ donation is already expected to take place and close family members are already aware of the deceased's wishes because the matter had already been brought up and discussed together with the deceased him/herself during his/her lifetime. Moreover, relatives might be reluctant to take a personal decision about the removal of organs, but they would find it easier to agree if they were simply confirming the intention of the deceased person¹⁰⁸⁴. This suggestion will also prevent incidences of family members being totally ignorant of the deceased's intention to donate organs, which is similar to leaving the final say to the family.

This situation normally leads to refusal to allow donation as, in cases of uncertainty, added to the responsibility of making a big decision when they themselves are also feeling vulnerable and distressed, the family might feel that the safest course of action is to refuse permission for organ donation¹⁰⁸⁵. The implication of the deceased not registering him/herself as an organ donor also invokes a belief within his family members that the deceased was against organ donation, and this is reinforced by the presumption that, if the deceased had wanted to donate his/her organs, he/she would have indicated such intentions during his/her lifetime¹⁰⁸⁶. As a result, fewer organs are being donated. Conversely, if family members are already aware of the deceased's wishes, hopefully, when the actual time comes, it will be easier for them to accept and honour the deceased's wishes to become an organ donor.

The two family witnesses could also play an influential role by explaining and clarifying the wishes of the deceased to the other members of the family, as it is always easier, more comfortable and convincing to listen to people who are close to us compared to doctors and nurses, who are considered total strangers. In practice, these two witnesses need not

¹⁰⁸⁴ Kennedy I, Sells R A, Daar A S, Guttman R, Hoffenberg R, Lock M, Radcliffe-Richards J and Tilney N, 'The Case for "Presumed Consent" in Organ Donation', (1998) *The Lancet*, Vol 351, May 30, 1650-1652, p.1651

¹⁰⁸⁵ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 4.1, p.8

¹⁰⁸⁶ TJ Tymstra, JW Heyink, J Pruijm and MJH Slooff, 'Experience of Bereaved Relatives Who Granted or Refused Permission For Organ Donation', (1992) *Family Practice-An International Journal*, Vol.9, No.2, Oxford University Press, 141-144

be present during the registration process, and are only required to sign the registration form, including supplying their brief personal and contact details so that they can be easily reached by those in authority. These witnesses must be aged 18 and above, sane, and have family proximity to the registered organ donor. Nonetheless, in cases where the potential organ donor has no family members at all or in cases where none of the family members is available to willingly come forward, provide support and become a witness, exceptions could be made. This additional requirement should not become an obstacle hindering people in making their altruistic organ donations. So it is recommended that the preference for having family members as witnesses be made flexible in these cases and that they might be substituted by those who are in close relationships with the deceased as well. This could be a close friend, a colleague, a close neighbour or maybe an employer, for example, as long as they are able to certify and demonstrate awareness of the person's whereabouts and can at least provide some brief information about the deceased. After the potential registered donor has filled in his/her particulars on the registration form, has indicated which organs he/she would like to donate, and obtained the signatures from the two witnesses, the completed form will then need to be submitted as usual.

It could be argued that this additional requirement of having to obtain two witnesses' signatures makes the registration process appear more rigid and complicated; the researcher believes, however, that if a person is seriously intending to donate his/her organs, this additional requirement will never prevent him/her from continuing to do so. It is actually not at all difficult to adhere to, especially in a Malaysian scenario where family members are normally close and reachable. This suggested requirement could also be seen as a test to measure ones' seriousness and willingness to proceed as an organ donor and should be considered a blessing in disguise as it respects the wishes of the individual and at the same time acknowledges the importance of family support.

The researcher strongly believes that this will be no hindrance to any person continuing with their altruistic intentions to officially become a registered organ donor; it will actually make things more certain and run more smoothly. As for the registered donor

him/herself, he/she could rest assured that his/her wishes to donate his/her organs will be honoured and carried out upon his/her death, without fear of his/her decision being overruled by the family later. However, the implementation of this additional witness requirement must not in any way prohibit the potential organ donor from retracting his/her decision to donate. To do this, he/she could simply inform the National Transplant Registry (NTR) of his/her intention to de-register and subsequently his/her name would be removed from the list of registered potential donors. He/she might inform the witnesses of this change of heart but it will, nevertheless, always be the responsibility of the NTR to inform the witnesses of any changes.

This witness requirement is also possible for online organ donor registrations. Here, the organ donor will enter his/her particulars online as usual and additionally state the name and brief details of the two family witnesses supporting his/her registration. Later, the NTR will contact these two witnesses to record their agreement and support. In cases where family support is clearly obtained, in the event of the death of the registered organ donor, the hospital can in fact implement the organ procurement procedures immediately, even without first informing the family members. This will reduce delays in procuring the donated organs while ensuring the possibility of a better outcome from the transplantation by facilitating earlier tissue-matching and other related procedures. However, in cases where the registered organ donor only managed to enlist a non-familial witness, the hospital will still need to try and contact the family of the deceased. This is not to obtain their consent, but is more a matter of courtesy and respect for them.

In relation to approaching families, change should be made to the purposes for so doing. The current practice now is that families are approached for their consent to organ donation; however, once families no longer have the power to overrule the deceased's wishes to donate organs, approaching them shortly before organ procurement procedures take place should be no more than a sign of respect and to keep them abreast of what is happening to the deceased's body. Hopefully, families would be more comfortable when approached on the issue and might accept it as a routine part of end-of-life care. It is absolutely crucial for the families to know and understand their new, limited role, and

that they are being approached only to further affirm organ procurement proceedings, and are no longer sought for their consent to the procedure. This does not in any way imply that they are disregarded; rather, it indirectly entails the attempt to fully honour and respect both the deceased and his family.

In a study conducted by Ashley et al. to increase donation consent rates in patients with prior Department of Motor Vehicle (DMV) donor designations, it was shown that modifying the approach to families, from seeking their consent to organ donation to asking them to honour the patient's wishes instead, had actually increased the organ procurement rate to an outstanding 100% result¹⁰⁸⁷. Before this approach was introduced, only 20 of a total of 24 families of patients having prior DMV designations proceeded with organ donation. This means that the remaining four families had dismissed the opportunity to proceed with the organ donations hoped for. However, after this modified approach was introduced, the families of all 19 DMV designated donors had consented to organ donation¹⁰⁸⁸.

This approach also signifies how a balance can be struck between providing respect and honour to the grieving family while at the same time ensuring that the deceased's wishes can still be carried out. However, in cases where family rejection is too strong and they cannot be persuaded to compromise, or they have perhaps even commenced legal proceedings to block such procurement from taking place, it is better to adhere to the family's wishes, as any compulsion used to proceed with organ donation despite the families' strong opposition will impact not only the patient, but also their families, who must cope with the sudden loss of the deceased. So, in such exceptional cases, it is important to maintain respect for the families as well. Consulting family members at the time of death could at least positively facilitate the process of obtaining details and

¹⁰⁸⁷ Ashley Britton Christmas, Eric J. Mallico, Gary W. Burris, RN Tyson A, Bogart, RN, Harry James Norton and Ronald F. Sing, 'A Paradigm Shift in the Approach to Families for Organ Donation: Honoring Patients' Wishes Versus Request for Permission in Patients With Department of Motor Vehicles Donor Designations', (2008) Volume 65, Number 5, *The Journal of Trauma Injury, Infection, and Critical Care*, 1507-1510.

¹⁰⁸⁸ *Ibid*

information¹⁰⁸⁹ about the potential donor's current medical and behavioural history, which plays an important role in ensuring the success of a transplant¹⁰⁹⁰.

Reports from the UK Organ Donation Taskforce showed that donor families themselves insisted on being involved in the decision to donate and on being allowed to make the decision that was right for them at that time¹⁰⁹¹. Surprisingly, even the organ recipients themselves felt that it was important to know that the family of the donor had been involved in the decision-making process and were also comfortable with it¹⁰⁹². Therefore, in our efforts to reduce family rejection of organ donation, it is equally crucial to ensure that all these families involved have a positive experience in the context of donation. These donor families' first-hand experiences of being involved in the deceased's organ donation process will obviously play an important role in sustaining future donation rates, both in the educational role that they play within their own communities and the formal roles they sometimes play in helping to educate healthcare professionals about their experience of the system itself¹⁰⁹³. "Based on reported experience in the USA, given the right circumstances, families appear motivated by what their deceased family member achieved through organ donation and this is commonly illustrated by the heroic status which is attributed to them"¹⁰⁹⁴. So, in short, we can see that, were the donor families to experience a positive and supportive environment in the decision-making process, their positive attitude towards the system would most likely spread and be shared with others in the community. However, if their experience were a total nightmare, more negative rumours would, without doubt, spread and surely jeopardize all our efforts to further promote organ donation.

¹⁰⁸⁹ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 253, p.50.

¹⁰⁹⁰ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 6.3, p.12

¹⁰⁹¹ *Ibid*, para 8.4, p.17

¹⁰⁹² *Ibid*

¹⁰⁹³ Magi Sque and Tracy Long, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 254, p.50.

¹⁰⁹⁴ *Ibid*

The researcher personally agrees that the deceased donor's wish to become an actual donor should be respected as it is part of upholding the principles of human autonomy. However, there remain some concerns: why does the same system not provide respect to the deceased when he/she did not express any consent to become an organ donor? Is it right to allow others, particularly the family, to decide on his/her behalf when he/she most probably did not want to become an organ donor in the first place? In cases where the deceased had actually informed any of his/her family members about his/her intention to become an organ donor, but had subsequently failed to officially register as one, this is still justifiable. The main concern lies particularly in cases where the deceased had remained silent and his/her real wishes are totally unknown: in a system where individual consent is considered pre-eminent, should we not also respect and uphold the human autonomy principles here? However, many will probably argue that, once families are not allowed to decide on behalf of their deceased family member, the organ shortage problem will consequently become even worse. Personally, the researcher agrees that that is a possibility; nevertheless, it would be much better if we could avoid this and not allow organ shortage problems to become an excuse for it. We should still consider the possibility that the deceased actually did not intend to donate his/her organs and might have his/her own personal reasons for this position.

In Malaysia, section 2(1) of the Human Tissue Act 1974 clearly requires the person him/herself, while alive, to express his/her wishes to donate his/her organs, either in writing or orally, and the same Act remains silent on providing authority for others to decide on his/her behalf upon his/her death. However, article 6.3.7 of the National Organ, Tissue and Cell Transplantation Policy does conversely give authority to the next of kin to decide on behalf of the deceased whether or not to donate his/her organs. The same happens in the UK where, by virtue of the Human Tissue Act 2004, in cases where the deceased had not expressed their intention to become an organ donor, the person nominated by the deceased or someone close to them (qualifying relationship) could also decide on their behalf¹⁰⁹⁵. With due respect, although revoking the power of the family to

¹⁰⁹⁵ The Human Tissue Act 2004 New Legislation on Human Organs and Tissue, <http://www.dh.gov.uk/prod-consum-dh/groups/dh-digitalassets/@dh>, viewed on 12 August 2009.

decide on behalf of the deceased seems impossible, and that it could possibly affect the number of organs procured, the researcher still believes otherwise; no matter how scarce the organ supply is, when a person does not register as an organ donor during his/her lifetime, the family members should no longer be allowed to decide on his/her behalf. Coincidentally, the Scottish Council on Human Bioethics (SCHB) supports the same view as it considers it crucial that organs or tissues should only be removed from a deceased person if this person had given his or her consent for the procedure. They also opined that the next of kin should not authorize the retrieval of organs when the individual had left no wishes, especially when an opting-in system is adopted¹⁰⁹⁶.

8.3 ROAD FATALITIES AS ORGAN RESOURCES

Another possible solution is to depend on the plentiful supply of organs available from road traffic accident victims. Despite actions taken by the government of Malaysia to reduce road fatalities, unfortunately it is still one of the most common causes of death among Malaysians aged between 15 and 64¹⁰⁹⁷. According to the Fourth Report of the National Transplant Registry 2007, 53% of the brain-dead donors between 1997 and 2007 were involved in motor vehicle accidents¹⁰⁹⁸. Therefore, if more organs from this group could be donated, Malaysia would no longer have to procure organs from donors who are less ideal, for example, those having a history of hypertension and /or diabetes, or reduced renal function at the time of retrieval, elderly donors¹⁰⁹⁹, donors with long ischemia time, non-heart-beating donors, split-liver deceased donors, and donors with infections and elevated creatinine¹¹⁰⁰. It would also no longer have to resort to

¹⁰⁹⁶ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1: Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 285, p.56.

¹⁰⁹⁷ Statistics on Causes of Death Malaysia 2005, National Registration Department, February 2009, <http://www.statistics.gov.my>, viewed on 22 August 2009.

¹⁰⁹⁸ Lela Yasmin Mansor, Cadaveric Organ and Tissue Donation, 2007, NTR Publications, <http://www.mst.org.my/ntrSite/download/report2007/Chapter%208%20-%20Cadaveric%20Organ%20and%20Tissue%20Donation.pdf>, p.184, viewed on 22 August 2009.

¹⁰⁹⁹ Rudge, C.J, 'Transplantation of Organs: Natural Limitations, Possible Solutions-A UK Perspective' (2003) 35 *Transplantation Proceedings* 1149-1150

¹¹⁰⁰ Abouna, G.M, 'Organ Shortage Crisis: Problems and Possible Solutions', (2008) 40 *Transplantation Proceedings* 34-38.

commercial organ transplants overseas¹¹⁰¹. A discussion of this issue is included in chapter 6 of the thesis.

8.4 ORGAN REGISTRATION FACILITY

An effective, computerized and user-friendly registration system plays a substantial role in encouraging more people to become organ donors. Therefore, it is significant for Malaysia to have a working registration system that can increase the number of registered organ donors as well as actual donors. However, if there is strong support from the public for organ donation, but this is not translated into a big increase in the number of registered organ donors, this would suggest that there might be some defects in the current organ registration system. It is absolutely crucial to have a systematic, well-managed and updated organ registration system that could cater for this purpose. The suggested registration system should list everyone who has registered as an organ donor and should be able to identify the current status of a person - whether he/she is in fact already a registered organ donor or otherwise¹¹⁰².

Ideally, in cases where a patient was dying, only by entering the person's national identification card number, for instance, would we be able to discover whether he/she was a registered organ donor or not. So, not only should the system facilitate registration, it should at the same time easily identify one's status because every related detail would be well-recorded and could be easily retrieved by those with the authority to do so. This would also ensure that organ donations were carried out promptly, apart from in exceptional cases where the deceased was physically or mentally unfit. However, adequate control over the data input should be routinely updated and protected to avoid any misuse of organ donors' confidential information. Once a system like this is adopted and operational, the public must be informed about its existence and functions, as this will boost their confidence about our organ donation system even more.

¹¹⁰¹ Hooi LS and Lela Yasmin Mansor, 1st.Report of the National Transplant Registry 2004, National Transplant Registry Malaysia, August 2005, p.128

¹¹⁰² Eike-Henner Kluge, 'Decisions About Organ Donation Should Rest With Potential Donors, Not Next of Kin', (1997) 157 *Can Med Assoc*, 160-160, p.160

Malaysia should follow the example of countries that have already taken initiatives to provide a simpler and more effective organ donor registration system. In the UK, for instance, the flexibility of the organ donation registering system is apparent, where the public is frequently prompted with the option to become organ donors not only through ordinary means such as the NHS Organ Donor Registry form, Organ Donation line and website but also when applying for driving licenses, applying for new passports, and registering with new GPs¹¹⁰³. As a result of this flexibility, 25% of those currently on the Organ Donation Register have actually been recruited through the driving license application form¹¹⁰⁴. Even private companies such as Boots offer this opportunity to people when they apply for their Advantage cards¹¹⁰⁵. It is reported that, since the UK Transplant partnership with Boots began in July 2000, over 1 million Advantage cardholders have already opted to join the Organ Donation Registry. This actually represents more than 6% of those currently on the register¹¹⁰⁶. This approach is helpful as it makes the public aware of the choices available to them and provides a flexible means for those interested to comfortably express their intention and register as organ donors in a more relaxed setting as they have ample time to think about it before deciding to give their ‘gift of life’ to others. Of course, the system cannot possibly ensure that everyone responds positively and subsequently becomes a registered organ donor, but at least it is striving to provide a greater opportunity for those who are willing to do so. This approach might at least stimulate everybody to consider organ donation even slightly; in any case, it might make them think about how they would wish their body to be treated after they die. Additionally, this step could also initiate discussions among the public themselves in rationalizing with one another the reasons why some of them are willing to voluntarily become organ donors. So, even if not everybody positively responds to this question at first, our aim, most importantly of all, is to familiarize them with the idea of donating organs while trying to provide a simple method of registering. It is indeed crucial to

¹¹⁰³ ‘Routes to Registration’, http://www.uktransplant.org.uk/ukt/how_to_become_a_donor/registration/routes_to_registrationh.jsp, viewed on 21st. May 2009

¹¹⁰⁴ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 14.7, p.32

¹¹⁰⁵ *Ibid*

¹¹⁰⁶ *Ibid*

provide and maintain a registration procedure that is user-friendly, practical and simple, yet informative enough to ensure an informed consent is obtained each time.

Malaysia would be advised to provide its driving license holders with the opportunity to register as organ donors each time they renew their driving licenses. The current practice in Malaysia is that a driving license can be renewed for a minimum of one year up to a maximum duration of five years. The minimum age requirement to apply for a driving license for vehicles such as cars, vans, buses and lorries is 18 years. However, the minimum age requirement to apply for a motorcycle license is only 16, which is actually below the age of majority required for one to become a registered organ donor. Therefore, this group, should they still want to register as organ donors, will be subject to the rules applicable to minors, and they will need to obtain support and consent from their parents first. So, when they go to the Road Transport Department (JPJ) to apply for motor licenses, these applicants must be accompanied by a consenting parent who is present to approve this action as well. However, the parents of these minors still have the right to refuse consent and object to their child's decision to become an organ donor, since they are still under parental care. Only after they have attained the age of 18 can they then register by themselves, albeit still without support and approval from their parents. To make this suggestion possible, arrangements must be made to ensure that, once a person registers to become an organ donor through this method, their consent is an informed one and they give it fully understanding the consequences of such commitments. Therefore, sufficient information regarding organ donation must also be provided by merely posting such relevant information on the wall at the JPJ¹¹⁰⁷, besides allowing opportunities for inquiries. It would be even better if we could provide brochures and posters all over the department as individuals could read them while awaiting their turn at the counters.

To further maximize the impact of these pamphlets and brochures it would be even more beneficial if they could be included together with the reminder letter from JPJ to renew their driving license or road tax, as this would allow ample time for them to consider the

¹¹⁰⁷ Amitai Etzioni, 'Organ Donation : A Communitarian Approach', (2003) *Kennedy Institute of Ethics Journal*, Vol.13, No.1, 1-18, pp. 9-10

matter and further assist them in making the best decision later. As such, designation for organ donation is considered informed consent¹¹⁰⁸ and this practice has in fact been applied in most states in the United States¹¹⁰⁹. However, to make possible this suggestion, full cooperation is needed from the JPJ to include this particular option to register as organ donors in their application forms. Positively, a study by Ashley et al. has proved that, by designating donors with the Department of Motor Vehicles (DMV), there was certainly an increase in the overall rate of consent for organ donation¹¹¹⁰. Further, in North Carolina, the heart symbol on the driver's license is accepted as legally sufficient consent to organ donation unless revoked by the donor¹¹¹¹. Of even greater significance, there is also a DMV website which enables individuals to log in and specify their organ donation status, and every designation is revocable at any time by those who have proclaimed themselves organ donors¹¹¹².

Another issue related to the organ donation registration system is the use of donor cards, which act as evidence proving that the carrier is a registered organ donor. In Malaysia, as explained earlier in chapter 3, when a person has officially registered their intention to become an organ donor with NTR, they will then receive a small, green organ donor card which must be carried by that person at all times, to allow quick identification of hi/hers wishes should the need arise. With due respect, the researcher considers this system ineffective as the card is easily lost and is often not carried by the organ donor at all times. For instance, only about 7% to 10% of all individuals in Germany who are in favour of organ donation carry with them a donor card¹¹¹³. Therefore, in a typical case where a registered organ donor is found fatally injured in a road accident for instance, if no organ donor card is found in his/her possession, and if no family member is aware of

¹¹⁰⁸ Ashley Britton Christmas, Eric J. Mallico, Gary W. Burris, RN, Tyson A. Bogurt, RN Harry James Norton and Ronald F. Sing, 'A Paradigm Shift in The Approach to Families for Organ Donation : Honoring Patients' Wishes Versus Request For Permission in Patients With Department of Motor Vehicles Donor Designations', (2008) *The Journal of TRAUMA Injury, Infection, and Critical Care*, Volume 65, Number 5, pp.1507-1510, p.1510

¹¹⁰⁹ *Ibid*

¹¹¹⁰ *Ibid*, p.1508

¹¹¹¹ *Ibid*, p.1509

¹¹¹² *Ibid*, p.1510.

¹¹¹³ Schutt GR, '25 Years of Organ Donation : European Initiatives to Increase Organ Donation', (2002) 34 *Transplantation Proceedings* 2005-2006

him/her being a registered potential organ donor, his/her chances of becoming an actual organ donor are obviously very slight. Only if his family gives their consent on his/her behalf to allow his/her organs to be procured will his/her wish to become an organ donor be realized. However, it would be a huge improvement were this card system to be replaced by an identification system incorporated in the person's driving license. This is because the driving license is itself a document that is practical in size and the driver is legally required to carry it while driving. This method has been applied for quite some time in the United States, particularly in Minnesota, where the phrase "Organ Donor = Yes" is written on the back of driving licenses which are in the form of small plastic cards, similar to credit cards; this system has been shown to work successfully¹¹¹⁴. Canada also uses driving licenses and healthcare cards to identify its organ donors¹¹¹⁵. Similarly, the government of China is also working with many organizations to set up an organ donation policy that will allow its people to express their wishes on their driving licenses¹¹¹⁶. Another alternative possibly applicable to Malaysia is to include the organ donor designation on the national identification cards. This suggestion is practical as Malaysia is now in the process of changing all its national identification cards into smart cards, which will be multipurpose, and will not only be used for citizen identification per se. To implement this, cooperation will be needed from the Jabatan Pendaftaran Negara (National Registration Office), which is the public organization in charge of the issuance of all national identification cards. Based on this study, from the total of 482 respondents involved, 77.2% (372 respondents) actually possessed driving licenses and are on the roads daily. One can imagine how many more people among the public at large are also using the roads every day, either as drivers, passengers or pedestrians. People are constantly moving about to reach different places near and far. So, the risk of accidents taking place is high as they can happen to almost anybody, anywhere and at any time of the day, perhaps while taking children to school or driving to work or even while going to the supermarkets and parks. Undeniably, as so many people are on the road, the chance of

¹¹¹⁴ Clause A Pierach, 'Some American Driving Licences Double as Organ Donor Cards', (1999) *BMJ* 318:399 (6 February)

¹¹¹⁵ Giles S, 'An Antidote To The Emerging Two Tier Organ Donation Policy In Canada: The Public Cadaveric Organ Donation Program', (2005) 31 *J. Med Ethics*, 188-191, p.188

¹¹¹⁶ Jiefu Huang, Yilei Mao, J Michael Millis, 'Government Policy And Organ Transplantation In China', (2008) *The Lancet*, vol.372, December 6, 1937-1938

any of these people being involved in any sort of road fatality is also highly possible. Therefore, it is suggested that immediate initiatives be taken to provide all these road users with the maximum opportunity to express and record their wishes on organ donation. This step could help avoid situations where people actually intend to donate their organs but are not facilitated to do so, and situations where registered organ donors are not identified because they were not carrying their donor identification cards.

If national identification cards or driving licenses were also allowed to function as organ donor cards, the researcher is positive that we could definitely identify more registered organ donors and subsequently allow more organs to be retrieved. For kidney donors, this early identification could facilitate prompt placement of *in situ* perfusion cannulae and decrease both warm and cold ischaemic times which would guarantee better function of the kidneys once harvested¹¹¹⁷. Additionally, there is a suggestion that credit card companies could also provide for organ donor identification on their respective credit cards¹¹¹⁸. This is a brilliant idea that should be considered although, compared to the driving license and the national identification card, a credit card is not something that everybody from all levels of society might have and, sometimes, one single person might have more than one credit card which could cause confusion if the data on each card were contradictory. However, it would be unfair to totally reject this proposition.

Conclusively, it is high time that Malaysia equipped itself with a more accurate, simple, flexible, and user-friendly method to facilitate people intending to register as organ donors. By having organ donation particulars expressed on either the national identification card or driving license, this indirectly becomes clear evidence and a direct means for the family and clinicians to share an understanding of the person's consent and wishes to become an organ donor¹¹¹⁹. Therefore, most importantly, the donors' intentions are clearly expressed and understood. However, were this method to be introduced in

¹¹¹⁷ Neil Davidson, 'Credit Card System May Improve Organ Procurement From Non Heart Beating Donors', (1998) *BMJ*; 317: 478 (15 August)

¹¹¹⁸ *Ibid*

¹¹¹⁹ Paul Murphy, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 276, p.54.

isolation, without taking steps to remove other barriers, such as family refusal, the system would still fail to function successfully. For instance, in the United States, although the desire of the deceased is expressed on a donor card or a driver's license, since the final decision still requires consent from the next of kin, the family refusal factor still accounts for a 50% procurement failure¹¹²⁰. To make things worse, potential donors without identification or an identifiable next of kin are usually not pursued for organ procurement procedures¹¹²¹. Therefore, it will be necessary to take other steps together with this suggestion.

8.5 THE NEED FOR A NATIONAL DATABASE

Malaysia needs to immediately set up an accurate and easily accessible computerized database which could link all the local hospitals with the National Transplant Registry and would be able to identify patients who are registered organ donors. So, from the moment a patient is admitted to the hospital, especially when admission is through the Accident and Emergency Division (A&E) and Intensive Care Units (ICU), this computerized database could easily identify the status of the patient – determining whether he/she is a registered potential organ donor or not - making it easier for the medical staff to stand by for any possible organ donation to take place whenever necessary. As time is of the essence in all organ donation cases, being equipped with such a system not only allows personal details of the patient to be easily assessable, but, most important of all, we can carry out a person's wish to become an organ donor, especially in a situation where they are no longer capable of letting others know and their family members are not aware of it either. However, this does not in any way mean that less attention or treatment should be provided to the patient; rather, it would enable the necessary steps to be taken sooner to ensure that a smooth organ procurement procedure takes place.

¹¹²⁰ Wendler D, Dickert N, 'The Consent Process for Cadaveric Organ Procurement: How Does It Work? How Can It Be Improved?' (2001) *JAMA* 285, pp.329-333.

¹¹²¹ Gary K.Shen, Patricia A.Niles, Ken E.Richardson, 'Presumed Consent: The Case of The John Doe Donor', (2004) 15 March Vol.77, No.5, *Transplantation*, pp.792-793

This database should also be able to indicate the latest updates and changes, including recent retractions by the registered donor. Therefore, a national computerized organ donor registry that lists registered organ donors' decisions along with their personal preferences is one of the most important initial steps required to ensure more systematic organ procurements¹¹²². This complete database would also work well as a complete record of donors and recipients and further facilitate the tracing of donors as well as recipients by the medical authority, particularly in cases of unexpected complications or adverse events. In the UK, the NHS Organ Donor Register was introduced in 1994¹¹²³. It is a confidential, computerized database that currently holds the names of over 16 million people who have decided to donate their tissue, organs or both. The register is used to check whether a person wishes to donate and what they want to donate. Donor cards are still used but, because they can be lost or stolen, the NHS Organ Donor Register is the best way to ensure all these wishes are permanently recorded¹¹²⁴.

8.6 ORGAN ALLOCATION

Fairness of the organ allocation system does have an impact on the public's acceptance of organ donation¹¹²⁵. A trusted organ resource allocation system is important for increasing the donation of organs and it influences the mortality rate of patients waiting for organs¹¹²⁶. People are more attracted towards organ donation when they are confident that the allocation system is fair, equitable and appropriate¹¹²⁷ and is not influenced by other factors such as age, sex, race, religion¹¹²⁸, usefulness to society and social

¹¹²² Wendler D, Dickert N, 'The Consent Process for Cadaveric Organ Procurement: How Does It Work? How Can It Be Improved?' (2001) *JAMA* 285, pp.329-333.

¹¹²³ http://www.uktransplant.org.uk/ukt/how_to_become_a_donor/questions/answers/answers_5.jsp#q13. viewed on 14 August 2009

¹¹²⁴ *Ibid*

¹¹²⁵ Barbera J. Daly, 'End-of Life Decision Making, Organ Donation, and Critical Care Nurses', (2006) 26 *Crit Care Nurse*, 78-86, p.82

¹¹²⁶ Bromberg J.S, and Halloran, P.F, 'Nine Things You Might Not Say or Hear in Transplantation', (2009) 9 *American Journal of Transplantation*, 11-13, Wiley Periodicals Inc.

¹¹²⁷ Guideline of the Malaysian Medical Council, MMC Guideline 006/2006, Organ Transplantation, <http://mmc.gov.my/VI/doc/organ%20Transplantation.pdf>, viewed on 17 August 2009

¹¹²⁸ Bruzzone,P, 'Religious Aspects of Organ Transplantation', (2008) 40 *Transplantation Proceedings*, 1064-1067

standing¹¹²⁹. Transparency about transplantation practice can influence the willingness of people to become organ donors¹¹³⁰.

In the current situation where organ supply is limited, it becomes even more crucial that organ allocation is handled with trust and responsibility. When the public at large has trust and faith in how the authorities deal with organ allocation issues, this indirectly contributes towards the organ procurement system's success. People know that their intended organs will be able to reach those in need through the proper channels and do justice to the patients. Therefore, ethical principles such as utilitarianism, justice and autonomy must be applied to further achieve this objective¹¹³¹. The utilitarian principle emphasizes that an action is considered right if it results in more good than the alternative action. So, medical indicators such as tissue-typing characteristics are relied upon, to predict better outcome and justify reasons why a particular recipient should receive an organ. However, the social worth of a person is not a relevant factor in itself¹¹³². The principle of justice will then allow consideration of other factors, not just utilitarian ones. This includes considering how long the patient has waited for the organ, even though another more recent patient may have a better tissue match¹¹³³. The autonomy principle will then allow allocated organs to be given to the next suitable waiting candidate in cases where a patient refuses to receive the organ allocated to him/her.

In most cases, all the above factors are considered together and finally a consensus is achieved¹¹³⁴. Those entrusted with the responsibility of distributing and allocating these organs are equivalent to trustees or stewards of these resources; thus, they must dispose their duty fairly¹¹³⁵. In the UK, the Organ Donation Taskforce identified that trust is

¹¹²⁹ Guideline of The Malaysian Medical Council Organ Transplantation, MMC Guideline 006/2006, <http://mmc.gov.my/vl/docs/Organs%20Transplantation.pdf>, viewed on 17 August 2009, p10

¹¹³⁰ Boulware LE, Troll MU, Wang NY, Powe NR, 'Perceived Transparency and Fairness of the Organ Allocation System and Willingness to Donate Organs : A National Study', (2007) *7 Am J.Transplant*, 1778

¹¹³¹ Guideline of The Malaysian Medical Council Organ Transplantation, MMC Guideline 006/2006, <http://mmc.gov.my/vl/docs/Organs%20Transplantation.pdf>, viewed on 17 August 2009, p.13

¹¹³² *Ibid*

¹¹³³ *Ibid*, p.14

¹¹³⁴ *Ibid*

¹¹³⁵ Bernard Teo, 'Is The Adoption Of More Efficient Strategies Of Organ Procurement The Answer To Persistent Organ Shortage In Transplantation', (1992) *Bioethics*, Vol.6, Number 2, 113-131, p.121

indeed the key to the success of the organ donation system in the UK; there is a risk that, once this public trust is shaken, the organ donor numbers will fall rapidly and it might take many years to recover from this situation¹¹³⁶. Therefore the Taskforce concluded that the need to maintain public confidence was one of its main considerations¹¹³⁷.

The 'solidarity model' proposed by Gubernatis and Kliemt does seem to be a practical and fair model of organ allocation. This model suggests that those willing to donate their organs should be granted relatively higher priority as organ recipients in the organ allocation process compared to non-organ donors, particularly while the system is coping with rationing problems in organ transplantation¹¹³⁸. This system could motivate people to consider organ donation more as it not only benefits patients who are in need of organs but additionally provides benefit to the donor him/herself in case he/she too needs an organ in the future. Having shown solidarity themselves, people can then demand that nobody hinder access to organs which others have willingly donated for them¹¹³⁹. Pattinson prefers to extend the priority to both the donor and their loved ones, as this would be an even greater form of encouragement for one to register as an organ donor¹¹⁴⁰. Moreover, this system suggests an important moral concept: if you are willing to give, then you shall receive and, because of your ability to give, your future potential will also be given the highest priority¹¹⁴¹.

Meanwhile, the extra merits given also function as a reward and a kind of non-monetary incentive for those who have agreed to commit themselves to organ donation. The system promotes fairness as, even though it gives priority to registered organ donors, others who are not registered donors are still given the chance to be included on the waiting list and are not totally deprived of the opportunity to receive the needed organs, although the fact

¹¹³⁶ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 4.6, p.9

¹¹³⁷ *Ibid*

¹¹³⁸ Gubernatis G, and Kliemt, H, 'Solidarity Model: A Way To Cope With Rationing Problems In Organ Transplantation', (2000) *Transpl Int* 13 [Suppl 1]: S607-S608

¹¹³⁹ *Ibid*

¹¹⁴⁰ Shaun D. Pattinson, '*Medical Law and Ethics*', (Sweet & Maxwell, London, 2006), p.437

¹¹⁴¹ Giles S, 'An Antidote To The Emerging Two Tier Organ Donation Policy In Canada: The Public Cadaveric Organ Donation Program', (2005) 31 *J. Med Ethics*, 188-191, p.190

that these dissenting minorities are treated at the expense of willing donors could still be mitigated.

The highest point on that additional scale should be granted to those who have served as living donors and have since lost their remaining kidney, while other points should include the length of time that has elapsed since a potential recipient declared their willingness to serve as a donor¹¹⁴². The researcher personally finds this model interesting as it is more like a win-win situation where both parties involved would obviously gain something in return, and it also seems easy to implement. However, giving the highest point on the scale to those who have become living donors and have consequently lost their remaining kidney indirectly encourages people to indulge in living donation whereas, in reality, it is always better to resort to cadaver donations as this reduces the possibility of healthy living people putting themselves at risk by donating their organs while still alive. However, it is reassuring to know that this organ allocation system still treats medical criteria as the dominant factor in organ allocation.

Similarly, on 7 March 2001, the Council of Europe adopted Recommendation No.R (2001/5) throughout Europe on the management of organ transplant waiting lists and waiting times, which also provides that organs and tissues allocated must be in conformity with transparent and justifiable rules according to the medical criteria¹¹⁴³. Similarly, a study conducted in Australia also demonstrated that organ allocation is vital to elicit community values and preferences towards organ donation¹¹⁴⁴. According to this study, the most influential factor in determining the priority rankings for organ allocation was the transplant recipient's age and prognosis.

¹¹⁴² Gubernatis, G. and Kliemt, H, 'Solidarity Model: A Way To Cope With Rationing Problems In Organ Transplantation', (2000) *Transpl Int* 13 [Suppl 1]: S607-S608

¹¹⁴³ Bopp, K, F, 'Safety and Quality Requirements in Organ Donation for Transplantation' (2003) 35 *Transplantation Proceedings* 995-996

¹¹⁴⁴ Colette J. Browning and Shane A. Thomas, 'Community Values and Preferences in Transplantation Organ Allocation Decisions', (2001) 52 *Social Science and Medicine*, 853-861, p.859

8.7 UPGRADING FACILITIES AND INFRASTRUCTURES

Malaysia first set up its National Transplant Resource Centre (NTRC) in November 2003. Therefore, all organ procurement matters are already regulated and controlled solely by NTRC. Similarly, in Spain, the first step taken to solve the organ shortage problems back in 1989 was to set up a centralized office known as Organismación Nacional de Trasplantes (ONT) to coordinate organ transplantation and donation matters at national, regional and local levels, with highly trained and qualified physicians taking on their roles as transplant coordinators, being responsible for detecting and identifying potential organ donors and also approaching families¹¹⁴⁵. So, the next step for Malaysia is to strengthen the position and functions of NTRC so that it is able to perform better at least at national level.

For a start, NTRC must be officially introduced to the Malaysian public so that they are aware of its existence and, therefore, can appreciate its functions more. NTRC must be promoted as the appropriate organization that specifically champions organ donation issues and is the best place to resort to for any issues related to organ donation and transplantation, rather than going to the hospitals. It is believed that, once NTRC has a stronger influence and is accepted by the public, it will be more influential and will play a bigger role in tackling issues such as improving donor identification and reducing family refusal rates. NTRC must shoulder the responsibility for ensuring that the public are aware of and understand all about the organ donation system adopted in Malaysia, including taking initiatives to improve the organ procurement process and organ donation rates¹¹⁴⁶.

NTRC must be able to deal with all kinds of different situations involving different types of donors and organs, including situations where there are conflicting wishes between the deceased donor and the next of kin. In clear cases where both the deceased and the next of kin are all in agreement on organ donation, NTRC must ensure that the donation

¹¹⁴⁵ Margaret Brazier and Muireann Quigley, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1: Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 190, p.40.

¹¹⁴⁶ Wendler, Dave and Dickert, Neal, 'The Consent Process for Cadaveric Organ Procurement: How Does It Work? How Can It Be Improved?' (2001) *JAMA*, Volume 285(3), pp 329-333.

intended can, if possible, take place rapidly to ensure the survival of the organs procured and to provide a better outcome for the organ recipient. So, organ donation involving these designated organs must proceed accordingly without unnecessary delays.

Similarly, in cases where the parties are not all in favour of organ donation, NTRC must guarantee that no such organ procurement will take place. In situations where the parties are in conflict, again NTRC must be prepared to provide solutions and assist by offering guidance on whose wishes should prevail. Therefore, all NTRC staff must be well-versed on the current law and protocols dealing with organ donation matters. In particular, in the current situation where family rejection is still considered authoritative in overruling the deceased's wishes, NTRC must at least try to approach and persuade the deceased's family to reconsider and finally accept the wishes of the deceased.

A drastic shortfall in the number of medical staff available is also a matter of great concern. Shortage of medical staff well-trained in organ transplantation *does* contribute to the existing organ shortage problem. According to Dr. Zakaria Zahari, due to lack of facilities and manpower his liver transplant team can only handle 50 cases each year¹¹⁴⁷. Sometimes, when a liver becomes available, it can actually be allocated to two or three organ recipients but, due to lack of facilities and trained expertise, only a part of the liver is utilized and the rest is wasted. Moreover, every time organ transplantation takes place, although we are able to solve one problem by providing the needed organ, at the same time we end up with a new set of problems, particularly the need for constant monitoring of both donor and recipient, controlling the level of organ rejections and maintaining their health conditions even long afterwards¹¹⁴⁸. Therefore, to ensure that all organs procured are maximally utilized and not simply wasted, immediate steps must be taken to further improve the number of well-trained staff in all areas of organ transplantation besides improving the facilities needed to cater for these urgent needs.

¹¹⁴⁷ Interview with Dr. Zakaria Zahari, Head Department of Paediatric Surgery, Paediatric Institute, Kuala Lumpur General Hospital, Malaysia on 18 January 2008

¹¹⁴⁸ *Ibid*

This issue of the lack of well-trained staff becomes even worse when some of the existing trained staff are transferred to other departments within the hospital, making it an endless problem¹¹⁴⁹. Even though there are suggestions to set up an independent transplant unit with permanent staff working within it, this suggestion is not yet practicable as the number of organ donations that actually take place is too small to justify the need for setting up such a unit¹¹⁵⁰. Therefore, the responsibility now lies with NTRC to ensure that all of their staff members are well-trained, as this is the only chance to enable a smoother organ procurement process to take place each time while reducing the risk of missing valuable opportunities to procure the available organs. There must be sufficient and fully-resourced organ retrieval teams available, working around the clock, 7 days a week, as potential organs can become available at any time and there are always possibilities of unwanted outcomes resulting from post-organ transplantation operations. These NTRC staff must be highly competent as they are responsible for identifying potential donors and, in some cases, approaching the grieving families, and are also required to provide clarification on any arising conflicts related to organ donation. Therefore, there can be no compromise over their quality: they must be well-trained and proficient in all aspects of organ donation as, until these are improved nationally, organ donation rates are unlikely to change¹¹⁵¹.

Moreover, failure to identify potential donors and initiate the referral and request process regarding the beliefs and attitudes of the families of potential donors represents another barrier to procuring more organ donations¹¹⁵². The Spanish system similarly emphasized the selection and training of all staff involved in the organ donation services; this became

¹¹⁴⁹ Interview with Jamaliah Kario, Senior Transplant Coordinator from National Transplant Resource Centre on 7th.January 2008.

¹¹⁵⁰ Interview with Dr. Ghazali Ahmad, Consultant and Head Department of Nephrology, Kuala Lumpur General Hospital, Malaysia on 12 February 2008

¹¹⁵¹ Jacquelyn K Lewin, 'Barriers to Organ Donation Improve Staff Infrastructure', (2009) *BMJ*, 338:b2013.

¹¹⁵² Barbera J. Daly, 'End-of Life Decision Making, Organ Donation, and Critical Care Nurses', (2006) 26 *Crit Care Nurse*, 78-86, p.82

one of the key factors contributing to their success¹¹⁵³. Additionally, an increase in the number of staff is necessary to provide care and support to the relatives of the donors¹¹⁵⁴.

The Department of Health End-of-Life Care Strategy which covers care at the end of life for adults in England fully supports and recognizes this need. Additionally, the Bolton Hospital Trust provides bereavement and donor support teams which offer support to relatives and staff in the immediate aftermath of a patient's death, including discussion of organ donation options whenever appropriate¹¹⁵⁵. Spain provides a 24-hour transplantation hotline with a single telephone number for the entire country, to provide instant access to its Organizacion Nacional de Trasplantes (ONT)¹¹⁵⁶. The UK is also preparing to set up a self-sufficient 24-hour organ retrieval team as part of its response to the taskforce recommendations and BTS reports¹¹⁵⁷.

Next, there must be improvements in the structure and working conditions of the transplant coordinator network¹¹⁵⁸. In Malaysia, as the number of registered organ donors is steadily increasing each year, more transplant coordinators need to be appointed, especially those who have professional management qualities and are able to uphold the national guidelines regulating transplantation procedures. It is recommended that at least one transplant coordinator be appointed to every state hospital in Malaysia, rather than depending on the NTRC alone to cater for all cases. State hospitals should be designated as alternatives as, normally, potential and actual donor activities are highly concentrated

¹¹⁵³ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1: Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 36, p.12.

¹¹⁵⁴ *Ibid*, para 263, p.52.

¹¹⁵⁵ Government Response to the House of Lords European Union Committee Report on 'Increasing the Supply of Donor Organs Within The European Union, 17th Report of Session 2007-08, September 2008, para 4.15, p.5

¹¹⁵⁶ Matesanz ,R and Miranda,B, 'Organ Donation-The Role of The Media and of Public Opinion', (1996) 11 *Nephrol Dial Transplant* : Editorial Comments, 2127-2128

¹¹⁵⁷ Emma Wilkinson, 'UK Government Plans Shake-Up of Organ Donation Services', (2008) *The Lancet*, vol.371, January 26, www.thelancet.com

¹¹⁵⁸ Rudge, C.J, 'Transplantation of Organs: Natural Limitations, Possible Solutions-A UK Perspective' (2003) 35 *Transplantation Proceedings* 1149-1150

in larger hospitals¹¹⁵⁹. Additionally, more resources should be maximally invested to improve the process of obtaining consent in these large hospitals.

This donor transplant coordinator will be responsible for attending the donor hospital from the time of the initial referral until after organ removal, including assessing the suitability of the potential donor, gathering medical, social and behavioural information about the potential donor, discussing the matter with the potential donor's family, calling in the organ retrieval team, attending organ removal procedures and arranging the last offices¹¹⁶⁰. They must also be able to remain on hand to support the donor family¹¹⁶¹. Research findings from the John Radcliffe Hospital Research, UK, discovered that consent was more likely to be given by the bereaved family to use their loved one's organs for transplants if a doctor was accompanied by a specialist transplant coordinator, as they are more highly-trained and possess certain social skills for discussing the organ donation matter in the best manner¹¹⁶². A study by Simpkin and colleagues also showed that consent rates were higher when the request for organ donation is made by staff from the organ procurement organization or transplant centre along with the hospital staff¹¹⁶³.

Additionally, the doctor's ability to approach the bereaved family has been identified as another important factor which influences the next of kin's decision on organ donation by their deceased loved ones¹¹⁶⁴. Not only do the family members feel more confident with the doctors but, at the same time, the doctors themselves also feel more equipped to approach individuals in situations following death, once they have been properly trained to deal with such situations. At the same time, joint commitments of NTRC and all doctors and donor coordinators placed in every hospital with critical care facilities must

¹¹⁵⁹ Ellen Sheehy, Suzanne L Conrad, Lori E Brigham et al, 'Estimating The Number of Potential Organ Donors In The United States', (2003) 7 *N Engl Med* 347, 667-674, p.667

¹¹⁶⁰ Government Response to the House of Lords European Union Committee Report on 'Increasing the Supply of Donor Organs Within The European Union, 17th Report of Session 2007-08, September 2008, para 4.12, p.13

¹¹⁶¹ *Ibid*

¹¹⁶² 'Doctors Warned Over Donor Consent', BBC News, <http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/8009053.stm>, 22 April 2009

¹¹⁶³ Simpkin A, Robertson L, Barber V, Young J, 'Modifiable Factors Influencing Relatives' Decision to Offer Organ Donation: Systematic Review', (2009) *BMJ*, 339:b991,(21 April).

¹¹⁶⁴ Schutt GR, '25 Years of Organ Donation : European Initiatives to Increase Organ Donation', (2002) 34 *Transplantation Proceedings*, 2005-2006

be promoted to ensure better coordination and communication among them at national level. Spain already practises the appointment of regional organ donation coordinators and coordinators in each hospital. These coordinators are in fact medical doctors with clinical authority and 80% are selected from those who are highly experienced and specialize in intensive care¹¹⁶⁵. They work full-time within the hospitals, championing organ donation issues while at the same time maintaining interactions with both intensive care units and transplant teams¹¹⁶⁶. However, each coordinator post is held for a duration of only two to three years and, afterwards, the post-holders easily move back into other jobs. This is to allow more new ideas to come in, avoid “burn out” and subsequently ensure that a more effective organ donation process takes place continuously¹¹⁶⁷. The UK government has also increased the number of transplant coordinators while expanding funding to strengthen the current network of donor transplant coordinators. By 2010, the UK aims to have a total of 250 donor transplant coordinators¹¹⁶⁸.

Another suggestion worth adopting is to avoid discussing donations at the same time that news of the death is conveyed¹¹⁶⁹. The John Radcliffe Hospital Research, UK, discovered that, by doing so, more optimistic responses to organ donation were obtained. Although it involves just a little extra time, there is a big difference in the results as families are three times more likely to provide consent and positively accept organ donation¹¹⁷⁰. In the researcher’s opinion, as the suggestion is simple and practicable, and as it only requires slight changes, particularly in timing, there would definitely be no harm at all in immediately adopting it in Malaysia.

¹¹⁶⁵ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 193, p.40.

¹¹⁶⁶ *Ibid*, para 186, p.39.

¹¹⁶⁷ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 193, p.40.

¹¹⁶⁸ *Ibid*

¹¹⁶⁹ ‘Doctors Warned Over Donor Consent’, BBC News, <http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/8009053.stm>, 22 April 2009, Viewed on 20 August 2009.

¹¹⁷⁰ *Ibid*

While more national campaigns promoting organ donation are carried out, there must also be sufficient facilities prepared to deal with any sudden increase in donations that might take place. It would be meaningless to inspire a massive flow of potential donors registering as organ donors but, because of weaknesses in the existing system, be unable to record and trace them in the future. Similarly, it would be such a waste if all the potential organs obtained could not be utilized due to lack of emergency services, lack of ICU beds and lack of qualified paramedics and doctors to identify, monitor and proceed with organ transplantation operations. Referring to Spain's experience, there were extra intensive care beds, and the number of organ donor coordinators was trebled in order to cater for the trebling in the number of organ donors¹¹⁷¹. So, in Malaysia, with its 14 separate states, all the state hospitals must at least have their own transplant teams, modern facilities and adequate ICU beds to facilitate organ donation procedures¹¹⁷². If this were initiated, the transplant team would no longer need to travel to all these states whenever organs are suddenly available, and the patients themselves would not need to be transferred to the Kuala Lumpur General Hospital, where the NTR is located, each time.

By increasing our ability and settings to handle such urgent cases, hopefully more organ transplants might take place simultaneously as there are plenty of staff members available to facilitate and further monitor the situation. There would no longer be any need to wait for the transplant team to become available, since more staff would be well-trained and the required facilities would also be available. To maximize referrals and requests for organ donation from donor families, other recommended steps include requiring all ICU units to refer all potential donors to the NTRC, auditing ICU deaths to monitor referrals and holding senior hospital administrators accountable if potential donors are not referred¹¹⁷³.

¹¹⁷¹ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 192, p.40.

¹¹⁷².Briggs, J.D, Crombie,A, Fabre,J, Major,E, Thorogood, J and Veitch P.S, 'Organ Donation in the UK : A Survey by British Transplantation Society Working Party', (1997) 12 *Nephrol Dial Transplant*, 2251-2257

¹¹⁷³ Vathsala,A, 'Improving Cadaveric Organ Donation Rates in Kidney and Liver Transplantation in Asia', (2004) 36 *Transplantation Proceedings*, 1873-1875

At the same time, efforts must be made to minimize difficulties with the organ donation process, especially for the donor family, by reducing psychological trauma, providing bereavement counselling and avoiding delays in funerals, as all this will not only provide solace for the donor families in their time of grief but also stimulate a positive attitude to organ donation in general¹¹⁷⁴. The UK has also appointed senior nurses as donor liaison officers, based at intensive care units, as part of its plan to reduce organ shortage. Up to the year 2003, 35 hospitals had appointed senior nursing staff trained in intensive care in order to increase local awareness of organ donation, ensure all necessary protocols and practices are complied with, and approach the potential donor's next of kin¹¹⁷⁵.

Having directives or checklists is also important to provide guidelines to the public and medical staff involved about certain steps that they need to take. For the public, the directive must provide information about how a person can officially register as an organ donor, the criteria required and where to register. Once all the steps stated in the directive have been complied with, the individual can rest assured that he/she has officially become a registered organ donor and has the right to have his/her wishes carried out if and when the time arrives.

A directive for the medical staff should, on the other hand, guide them towards facilitating a smooth organ donation procedure through a standardized protocol. It should start from the very first moment when potential organ donors are identified, including the process of approaching and informing families and allocating organ recipients, up until the final stage where the transplant procedures will eventually take place. Having such directives could also help provide clarity, for instance in matters related to deciding patient care and treatment, the diagnosis of death, and maintaining the quality and safety of the procured organs. Not only would it assist the staff in making sound decisions but, indirectly, they would feel supported and could work freely within a clear, unambiguous framework of good practice. For example, the Academy of Medical Royal Colleges

¹¹⁷⁴ *Ibid*

¹¹⁷⁵ Rudge, C.J, 'Transplantation of Organs: Natural Limitations, Possible Solutions-A UK Perspective' (2003) 35 *Transplantation Proceedings* 1149-1150

(AMRC) received full support from the UK government to produce an updated Code of Practice for the diagnosis of death¹¹⁷⁶, for the same purpose¹¹⁷⁷. Once all this becomes routine and part of the organ procurement system itself, hopefully the medical staff involved will be clearer about their duties and responsibilities and will be more confident about approaching potential organ donors and their respective families for consent.

Recently, it was reported by the European Union Commission that, in many cases, the non-availability of donor organs is partly the result of the medical staff's attitude of never considering organ donation a serious issue. Therefore, the option of donation is never presented to the patient's relatives, and no evaluation is ever made of the suitability of the patient's organs for donation¹¹⁷⁸. This again proves the importance of raising working directives on organ donation among the medical personnel first, before further addressing the public at large on the same issue. These directives will function as a checklist that needs to be referred to and consulted every single time there is any possibility of organ donation taking place. However, it must be clear that these directives should be designed to further facilitate the process and should never become something that restrains or complicates the existing organ procurement procedures.

So, a balance must be struck to ensure that these directives do not become a burden or make organ donation a complicated matter. For instance, they should not cause clinically accepted organs to be rejected just because they do not comply with the high standards of quality and safety put forward. Ms Lesley Bently, Lay Chair of the Patient Liaison Group of the Royal College of Surgeons, even suggested that, in some cases, where the patient has great difficulty in finding an organ, an organ of less than the highest quality might possibly be considered¹¹⁷⁹. In short, these directives must not be tied up with bureaucracy

¹¹⁷⁶ A Code of Practice for the Diagnosis and Confirmation of Death, Academy of Medical Royal Colleges, 10 January 2008, <http://www.aomrc.org.uk/publications/reports-guidance>, viewed on 18 May 2011.

¹¹⁷⁷ Government Response to the House of Lords European Union Committee Report on 'Increasing the Supply of Donor Organs Within The European Union, 17th Report of Session 2007-08, September 2008, p.3

¹¹⁷⁸ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 36, p.12.

¹¹⁷⁹ *Ibid*, para 118, p.27.

nor be too rigid. Conversely, a well-balanced and flexible set of directives, added to the co-operation received from all levels of society, could in due course achieve a standardized and harmonized approach to organ donation. The key to a successful transplant process is to simultaneously improve and upgrade organization, cooperation and professional skills¹¹⁸⁰.

8.8 IDENTIFYING MORE POTENTIAL ORGAN DONORS

If we are to rely largely on brain-dead patients for potential organ donations, particularly patients who die as a result of sudden, traumatic and premature death¹¹⁸¹, all Intensive Care Units (ICU) and Accident and Emergency (A&E) departments in hospitals must be able to cope with such availability¹¹⁸². Findings from an audit of death undertaken in ten A&E departments in North Thames region, UK, discovered a huge potential pool of organ and tissue donors, but this source is not being utilized. Key healthcare professionals involved in the care of potential donors, including A&E staff, anaesthetists, neurosurgeons, emergency trauma teams, nurses and other medical staff, must be prepared at all times in case a potential donor suddenly becomes available. The involvement of in-house transplant coordinators in particular, at various trauma departments, is reported to significantly increase family consent rates^{1183,1184}. However, the fact that the family of the patient had not had sufficient time to establish and build their relationship with the medical and nursing staff makes it quite difficult to raise the issue of organ donation.

¹¹⁸⁰ Venettoni S, Di Ciaccio P, Ghirardini A, Mattucci D, Santangelo G and Nanni Costa A, 'Successful Models on Organ Procurement', (2003) 35 *Transplantation Proceedings*, 999-1001

¹¹⁸¹ Aubrey,P, Arber,S and Tyler,M, 'The Organ Donor Crisis: The Missed Organ Donor Potential from The Accident and Emergency Departments' (2008) 40 *Transplantation Proceedings*, 1008-1011

¹¹⁸² *Ibid*

¹¹⁸³ Shafer TJ, Davis KD, Holtzman SM, et al., 'Location of in-house Organ Procurement Organisation Staff in Level 1 Trauma Centres Increases Conversion of Potential Donors to Actual Donors', (2003), 75 *Transplantation*, 1330-1335.

¹¹⁸⁴ Shafer T, Wood RP, Van Buren CT, et al, 'An In-House Coordinator Program to Increase Organ Donation in Public Trauma Hospitals, (1998) 8 *J Transplant Coordination*, 82-87.

Moreover, the illness of the patient is normally sudden and can lead to premature death¹¹⁸⁵. So, it is absolutely crucial to intensify donor detection at hospital level¹¹⁸⁶ and to be prepared to handle such sudden availabilities of potential organ donors. Although there is a possibility that the bereaved family might refuse organ donation when approached, the medical staff must not consider this a failure. Rather, the real failure occurs when these people are never given a chance to say 'yes' or 'no' in the first instance. Nevertheless, many relatives still wish to be approached and to discuss the possibility of organ donation. Studies show that relatives actually do not feel offended or distressed as they understand that health professionals have a responsibility to ask; instead, they feel sympathetic to the healthcare professionals as they realize that the task of bringing up such a big matter in such a situation is undeniably difficult¹¹⁸⁷.

There is also a recommendation to carry out brain death testing on all patients in whom brainstem death is a likely diagnosis, even if organ donation is an unlikely outcome¹¹⁸⁸. Performing a brainstem death test is good medical practice for suspected brainstem death patients as, once brainstem death is confirmed, treatment should be ceased immediately and the families of the deceased should subsequently be offered the option of organ donation¹¹⁸⁹. Based on the Potential Donor Audit carried out by UK Transplant, it was identified that the omission of brainstem death testing for all potential organ donors leads to a significant loss of donor organs¹¹⁹⁰. Specifically, the Audit revealed that up to 1,288 patients per year are potentially suitable for organ donation, but the opportunity was

¹¹⁸⁵ *Ibid*

¹¹⁸⁶ Schutt GR, '25 Years of Organ Donation : European Initiatives to Increase Organ Donation', (2002) 34 *Transplantation Proceedings* 2005-2006

¹¹⁸⁷ Magi Sque, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 247, p.50.

¹¹⁸⁸ R 7, 14 Recommendations made by the Organ Donation Taskforce, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, p. 42.

¹¹⁸⁹ Simon Bramhall, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 232, p. 48

¹¹⁹⁰ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 197, p.41.

missed because brainstem death testing was not carried out¹¹⁹¹. Additionally, every year, between 400 and 600 patients in intensive care units, for whom diagnosis of brainstem death was likely, were never diagnosed; in the opinion of the auditors, there was no particular reason for this¹¹⁹².

This weakness has caused fewer potential organs to be procured, due to the fact that they are neither considered nor identified. Consequently, no referrals were made to the respective organ coordinators either. However, in carrying out this test, the standards for certifying brainstem death must be strictly complied with. Therefore, these tests will only be carried out twice, at separate times and by different doctors, neither of whom must be a member of the transplant team, once it is established that the patient has suffered irreversible brain damage. If the second set of tests confirms no evidence of brainstem activity, it is only then that the patient is declared dead¹¹⁹³.

The Scottish Council on Human Bioethics has taken a step further by suggesting that a specific provision should exist which allows physicians to remove organs for transplantation only after they are satisfied that brainstem death tests have been performed and recorded properly¹¹⁹⁴. In practice, critical-care teams are encouraged to notify the donor transplant coordinator regarding all patients whose condition may lead to brainstem death-testing¹¹⁹⁵. Once this has been confirmed, the wishes of the patient in respect of organ donation are identified and, if necessary, further appropriate clinical tests are conducted. Subsequently, organ donation will proceed if consent for it has been

¹¹⁹¹ Simon Bramhall, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 197, p. 41

¹¹⁹² Paul Murphy, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 197, p.41.

¹¹⁹³ Government Response to the House of Lords European Union Committee Report on 'Increasing the Supply of Donor Organs Within The European Union, 17th Report of Session 2007-08, September 2008, para 4.8, p.12

¹¹⁹⁴ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 233, p. 48

¹¹⁹⁵ Government Response to the House of Lords European Union Committee Report on 'Increasing the Supply of Donor Organs Within The European Union, 17th Report of Session 2007-08, September 2008, para 4.9, p.12

established. Already implementing this positive approach, the University Hospitals Birmingham NHS Foundation Trust has been automatically referring patients diagnosed as brainstem-dead to in-house donor coordinators and then subsequently approaching all relevant family members¹¹⁹⁶. For some time, Spain and the USA have both been practising this strategy which allows early referral of all possible donors to trained donor personnel to ensure that full support is provided if there is any possibility of consent and donation. This approach enables contact with potential donor families even before the subject of donation is brought up, which supports the building of trust and caters better to the needs of all families of potential donors¹¹⁹⁷.

Lastly, a proper pre-transplant evaluation of potential donors is necessary¹¹⁹⁸. Through this evaluation, sufficient information could be gathered to weigh and balance the potential risks or benefits arising from the transplant taking place, while further ensuring that the organs procured were of good potential and quality¹¹⁹⁹. Consequently, when all the risks and characteristics of the potential organs had been identified and documented, it would be easier to decide whether to proceed with the organ donation and allocate it to any suitable recipient. Although there are always certain risks associated with procured organs, it might be beneficial to weigh the possible risks against the consequences of not receiving a transplant at all. In other words, we cannot afford to be too selective and demanding although this does not in any way mean that the quality and safety aspects of the procured organs would be compromised. Generally, in most cases the overall benefits of an organ transplant are high but the clinician and potential recipient must play their important roles in deciding where, in a particular case, the balance of risk to benefit lies and whether an organ should be accepted for transplantation or not¹²⁰⁰.

¹¹⁹⁶ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 15.4, p.35

¹¹⁹⁷ *Ibid*

¹¹⁹⁸ Commission Communication: Organ Donation and Transplantation: Policy Actions at EU Level, May 2007, cited in the House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 211, p.44.

¹¹⁹⁹ *Ibid*

¹²⁰⁰ Government Response to the House of Lords European Union Committee Report on ‘Increasing the Supply of Donor Organs Within The European Union, 17th Report of Session 2007-08, September 2008, p.5

8.9 INCENTIVES

Another suggestion that could help increase organ donation in Malaysia is to offer incentives to registered potential organ donors and actual organ donors alike, especially when altruism alone seems to have failed to increase organ donation rates¹²⁰¹. Although rewarded gifting is generally mentioned in the Malaysian Medical Council Guidelines on Organ Transplantation, the council has yet to reveal its stance either to firmly support or oppose incentives being given to organ donors, particularly living donors¹²⁰². The incentive recommended here should not be treated as equivalent to putting a price on the organs donated or the willingness of a person to do so, but rather as a sign or gesture of appreciation to those willing to come forward and contribute their organs for others. This initiative should be seen as a symbol of gratitude for their spirit of altruism and voluntariness, and such rewards should come solely from the government or charitable organisations and not even partly from the recipient¹²⁰³. This is because, once any organ is donated to a patient who is also a member of society, society should feel an obligation to provide compensation for this service¹²⁰⁴. This concept is similar to legal benefits provided to war veterans or firemen injured on duty for any injury or loss suffered by them while defending the country and risking their lives for others¹²⁰⁵, or to monetary rewards for dedicated teachers¹²⁰⁶.

The giving or acceptance of such rewards does not commodify the recipient nor diminish the value of the organ contributed to society, nor cause loss of dignity¹²⁰⁷. Rather, it may be regarded as a necessity to minimize the level of exploitation that already exists in

¹²⁰¹ A. Vathsala, 'Improving Cadaveric Organ Donation Rates in Kidney and Liver Transplantation in Asia', (2004) 36 *Transplantation Proceedings*, 1873-1875

¹²⁰² Guideline of the Malaysian Medical Council, MMC Guideline 006/2006, Organ Transplantation, <http://mmc.gov.my/VI/docs/Organ%20Transplantation.pdf>, viewed on 17 August 2009, p.11

¹²⁰³ Ghods A.J, 'Changing Ethics in Renal Transplantation : Presentation of Iran Model', (2004) 36 *Transplantation Proceedings*, 11-13

¹²⁰⁴ Hou S, 'Expanding the Kidney Donor Pool : Ethical and Medical Considerations', (2000) 58 *Kidney International*, 1820

¹²⁰⁵ *Ibid*

¹²⁰⁶ de Castro,L.D, 'Commodification and Exploitation : Arguments in Favour of Compensated Organ Donation', (2003) 29 *J.Med Ethics*, 142-146, p.143

¹²⁰⁷ *Ibid*

current organ procurement systems¹²⁰⁸. In a study conducted in Pennsylvania to find out what the public thought about issues relating to incentive and benefits given in exchange for organ donation, it was found that, out of five types of benefits suggested including funeral benefits, charitable contributions, travel/lodging expenses, direct payment and medical expenses, direct payment received the lowest level of support¹²⁰⁹. This was mainly due to the belief that monetary incentive seemed to dishonour the spirit of altruism in organ donation and commercialize the value of human life¹²¹⁰. Some people find direct payment to a donor or to the surviving family members, crass or unseemly¹²¹¹. There is also a worry that financial incentives might put undue pressure, especially on the poor, to become society's supplier of organs¹²¹². Therefore, considering all this, it would be appropriate to suggest that any incentives recommended for Malaysia should be non-financial incentives, which are sometimes called "moral" incentives.

There are proposals to award commemorative certificates or plaques to those who donate organs, expressing the appreciation of the people and the state as well as creating a donor's memorial; however, although these would merely express the moral approval of society, their effectiveness in increasing the supply of organs sufficiently is doubtful¹²¹³. The "rewarded gifting" should be something more tempting, which might possibly make a person more attracted to considering organ donation, especially when it is still an uncommon practice among the Malaysian public. Therefore, it should preferably be something of monetary value that could be provided to the donor or his family (for deceased donors) but should not in any way amount to payment for the organs. Some proposals that have been put forward include providing insurance policies that would pay the beneficiary if, and only if, the organs are ultimately procured; alternatively the incentive might be in the form of token payments given to potential organ sources for a

¹²⁰⁸ *Ibid*, p.142

¹²⁰⁹ Bryce CL, Siminoff LA, Ubel PA, Nathan H, Caplan A, Arnold RM, 'Do Incentives Matter? Providing Benefits to Families of Organ Donors', (2005) *Am J. Transplant* 5(12), 2999-3008

¹²¹⁰ *Ibid*

¹²¹¹ Robert M. Veatch, 'Why Liberals Should Accept Financial Incentives For Organ Procurement', (2003) *Kennedy Institute of Ethics Journal*, Vol.13, No.1, 19-36, p.21

¹²¹² *Ibid*, p.19

¹²¹³ *Ibid*

commitment to provide organs upon death, such as a discount on one's driver's license if one ticks the organ donor box¹²¹⁴.

The panel of ethicists, organ procurement organization executives, physicians and surgeons convened by the sponsorship of the American Society of Transplant Surgeons unanimously rejected direct payment or tax incentives as the type of potential incentives to be offered, as this would violate the ideal standard of altruism and commercialize the value of human life by commodifying donated organs¹²¹⁵. In the Netherlands, people who agree to give up organs benefit from a 10% discount on health insurance premiums, while in Oregon, United States, discounts are given on funeral costs¹²¹⁶. A similar approach is also currently used by anatomy institutes in Switzerland to compensate people who leave their bodies to scientific research¹²¹⁷.

For Malaysia, the researcher suggests that the incentive be in the form of providing free medical treatment and first-class ward facilities starting from the day a person registers as a potential organ donor up until the time they actually donate the intended organs. In Malaysia, the cost of treatment in government and private hospitals is not provided free of charge, though the latter is even more expensive. The medical cost charged, either for treatment, medication or hospitalization, differs according to the group of people treated, depending on whether one is a citizen, a foreigner, a government servant or pensioner, or working in the private sector¹²¹⁸. Three different classes of wards are available, namely first-class, second-class and third-class¹²¹⁹; these differ in terms of facilities and privacy. For example, a first-class ward will have only one or two patients in a single room, while the third-class ward will be a large room shared by around 8 patients.

¹²¹⁴ *Ibid*, p.22

¹²¹⁵ Robert Arnold, Steven Bartlet, James Bernat, John Colonna et al, 'Financial Incentives For Cadaver Organ Donation : An Ethical Reappraisal', (2002) *Transplantation Forum*, Vol.73, No.8, April 27, 1361-1367

¹²¹⁶ Study Urges New Incentives for Organ Donors, 27 July 2010, http://www.swissinfo.ch/eng/science_technology/study_urges_new_incentives_for_organ_donors.html?cid=18213278, viewed on 30 June 2011

¹²¹⁷ *Ibid*

¹²¹⁸ Perintah Fi (Perubatan) 1982, <http://www.myhealth.gov.my>, viewed on 3 February 2010.

¹²¹⁹ *Ibid*

This incentive of providing free medical treatment and first-class ward facilities might simply be applicable to living organ donors, as they themselves will be able to enjoy this privilege during their lifetime. But how can we provide these incentives to cadaver donors, particularly in cases where the decision to donate organs has been made by the deceased's next of kin? The researcher personally disapproves of the fact that families can decide on organ donation on behalf of the deceased party; however, because this is still the current practice in Malaysia, perhaps the free medical treatment and first-class ward facilities offered should then be extended to the donor's close family members, which includes their parents, spouse and children, for a limited period of 5 years for instance. This type of privilege is actually already provided to all government officers in Malaysia: their parents, spouses and children are also eligible to claim such privilege as long as the respective person remains in service as a government officer¹²²⁰. However, this privilege will cease when the person has retired or discontinues their service as a government officer¹²²¹. However, it must also be made clear that all organ donors are already exempted from all hospital charges related to the organ donation procedure agreed, starting from the first day they are admitted to the hospital, as long as it is done at a government hospital¹²²². However, for any organ or tissue donation procedures carried out at a private hospital, all the costs incurred from the day the donor is admitted until he/she passes away, are to be borne by his/her family or relatives¹²²³.

Providing financial incentives is nevertheless quite controversial. Consider the example of Iran where, because monetary compensation is given, it is now hard for the authorities to deny the possibility that people are donating organs only for the sake of obtaining a monetary reward to ease their poverty¹²²⁴. It has also become a common phenomenon that many young and impoverished Iranians agree to donate organs just to pay off their

¹²²⁰ Jabatan Perkhidmatan Awam Malaysia official website, <http://www.jpa.gov.my>, viewed on 20 October 2010

¹²²¹ *Ibid*

¹²²² Section 16(3) Perintah Fi (Perubatan) 1982. This is applicable from 29 December 2003, as stated in the letter from the Ministry of Finance, KK/BP(s) 09/692/79 Jld 3. S.K.4/2003(4), <http://www.myhealth.gov.my>, viewed on 3 February 2010

¹²²³ *Ibid*

¹²²⁴ Larijani, B, Zahedi, F, and Taheri, E, 'Ethical and Legal Aspects of Organ Transplantation in Iran' (2004) 36 *Transplantation Proceedings*, 1241-1244, p.1242

debts. In fact, 84% of the donors are categorized as poor and the remaining 16% are from middle-class society¹²²⁵. At this point, money seems to destroy the spirit of altruism and voluntariness, making it seemingly harmful to offer financial incentives in exchange. Perhaps this contributed to the decision made by both the UK and US to prohibit the offering of financial incentives through their Human Tissue Act 2004 and 1984 Uniform Anatomical Gift Act/ National Organ Transplant Act respectively¹²²⁶. However, even though the free medical treatment and first-class wards incentive is given in advance, and there is a possible risk that the potential donor might withdraw his/her intention of becoming an organ donor after already enjoying the incentive, it is still fair, as their organs can be procured until the moment they withdraw, since only after a withdrawal will their names be automatically removed from the registered organ donor list and any privileges cease.

Another possible incentive is the offer to contribute towards the donor's funeral expenses. An amount of RM2500 payable by the Malaysian government would be sufficient. The fixed amount offered may look like a payment for organs rather than compensation for costs incurred¹²²⁷; however, this could be rebutted on the basis that the amount given is not at all equivalent to the price of the organs donated. Moreover, the funeral benefit offered is optional and is only a small token of appreciation¹²²⁸. Previously, in Pennsylvania, with support from the American Society of Transplant Surgeons, a small sum of \$300 was provided as partial reimbursement of funeral expenses to the deceased donor's family. This sum was kept small as the intention was only to convey appreciation for the donation and it was not meant to be treated as payment for the organs. However, this program had to be halted due to concerns that the provision of funeral benefits violated the Federal Law¹²²⁹. Nevertheless, the American

¹²²⁵ Ghods AJ, Ossareh S, Khosravani P, 'Comparison of Some Characteristics of Donors and Recipients in a Controlled Living Unrelated Donor Renal Transplantation Program' (2001) 33 *Transplantation Proceedings*, 2626

¹²²⁶ 'Should Organ Donors Be Paid?', (2008), 6 *International Journal of Surgery*, 181-183

¹²²⁷ Robert M. Veatch, 'Why Liberals Should Accept Financial Incentives for Organ Procurement', (2003) *Kennedy Institute of Ethics Journal* Vol.13, No.1, 19-36, p.24.

¹²²⁸ Francis L. Delmonico, Robert Arnold, Stuart J. Younger, 'Ethical Incentives-Not Payment-For Organ Donation', (2002) *N. Engl J Med*, 347 : 1382, Oct 24, Correspondence

¹²²⁹ 'Should Organ Donors Be Paid?', (2008) 6 *International Journal of Surgery*, 181-183

Society of Transplant Surgeons still believes that funeral reimbursements are ethically preferable to direct payments as incentives for organ donors¹²³⁰, because this indirectly preserves the gift concept in organ donation and essential ethical perception of gratitude in organ exchange¹²³¹. Similarly, in the Kuwaiti model, reimbursements were provided for travel and burial expenses for the family of the deceased donor. This managed to increase the percentage of transplants per year from 5% to 25% and stopped Kuwaiti citizens from purchasing kidneys from India and Asian countries¹²³². Similarly, organ donation professionals in Spain have the option of offering donor families reimbursement for funeral costs in return for their agreeing to donate organs, although many prefer not to exercise this option¹²³³.

Under a federal scheme in the United States, the cost of travelling, hotel expenses and loss of wages, particularly for the living donor and also the family of the deceased donor, is provided to increase organ supply¹²³⁴. This type of incentive was taken up by the Department of Health and Human Services when they approved \$8 million over 4 years to help pay the financial costs incurred by living donors, and each individual organ donor could be reimbursed with sums ranging from \$500 to \$3500¹²³⁵. Again, this alternative was proved effective as organ donations from living donors increased, although payment for loss of wages was not included¹²³⁶ in this scheme¹²³⁷.

¹²³⁰ Robert Arnold, Steven Bartlet, James Bernat, John Colonna et al, 'Financial Incentives For Cadaver Organ Donation : An Ethical Reappraisal', (2002) *Transplantation Forum*, Vol.73, No.8, April 27, 1361-1367

¹²³¹ Patrick D.Carson, 'The 2004 Organ Donation Recovery and Improvement Act. How Congress Missed an Opportunity to Say 'Yes' to Financial Incentives for Organ Donation', (2006-2007) *Journal of Contemporary Health Law and Policy*, 144

¹²³² Abouna GM, 'Ethical Issues in Organ Transplantation', (2003) 12 *Med Principles Prac*, 54

¹²³³ Megan Crowley-Matoka and Margaret Lock, 'Organ Transplantation in a Globalised World', (2006) *Mortality*, Vol.11. No.2, May, 166-181, p.178

¹²³⁴ Abouna GM, 'Organ Shortage Crisis: Problems and Possible Solutions', (2008) 40 *Transplantation Proceedings*, 34-38.

¹²³⁵ Wittenauer C. Grant to Ease Financial Burden on Organ Donors, Associated Press, December 11, 2006 cited from Abouna GM, 'Organ Shortage Crisis: Problems and Possible Solutions', (2008) 40 *Transplantation Proceedings*, 34-38.

¹²³⁶ *Ibid*

¹²³⁷ Under section 3 of the Organ Donation and Recovery Improvement Act (ODRIA), 42 U.S.C.274f, it establishes the authority and legislative parameters to provide reimbursement for travel and subsistence expenses incurred towards living organ donation. The National Living Organ Donor Association Center (NLDAC) operates this program and it provides reimbursement unless the donor can receive reimbursement from any of the following sources:

Alternatively, the incentive could also be in the form of a benefit of a set amount that would reward the deceased's donor's estate upon the family's decision to donate the organs¹²³⁸. This would then result in 'familial benefit', since the remuneration could be used by the family to help pay for the funeral or hospital costs, or as a donation to the deceased's favourite charity, or could simply remain with the estate. One way or another, the remuneration would yield emotional or psychological benefit if the funds received were used to memorialize the deceased¹²³⁹.

This simple step of offering incentives has become fruitful in increasing the number of organ donors in many countries, so it is time for Malaysia to take a similar step. Moreover, the fact that Muslim scholars considering the ethics of organ donation in six Islamic countries, including Kuwait, Saudi Arabia, Iran, Egypt, Lebanon and Oman, supported this idea of providing reward in return for organ donation¹²⁴⁰ strengthens this proposal, as the majority of Malaysians are also Muslims. With due respect, the researcher disagrees with Veatch who argues that indirect incentives will not work and are morally deceptive. Veatch also opposes all efforts to provide planned systematic "rewards" or "gifts", or to provide medical or burial expenses as, according to him, such plans are merely gimmicks covering the fact that financial incentives are actually being paid¹²⁴¹. The researcher still believes that the incentive suitable for Malaysia is to provide free medical treatment and first-class wards, including contributing towards the donor's funeral expenses.

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- 1) any state compensation program, any insurance policy, or any Federal or state health benefits program;
 - 2) any entity that provides health services on a prepaid basis; or
 - 3) the recipient of the organ- quoted from National Living Donor Assistance Center, <http://www.livingdonorasstance.org/potentialdonors/eligibilityguidelines.asp>, viewed on 18 May 2011.

¹²³⁸ Patrick D.Carson, 'The 2004 Organ Donation Recovery and Improvement Act. How Congress Missed an Opportunity to Say 'Yes' to Financial Incentives for Organ Donation', (2006-2007) *Journal of Contemporary Health Law and Policy*, 144

¹²³⁹ *Ibid*

¹²⁴⁰ Larijini,B, Zahedi,F, and Taheri,E, 'Ethical and Legal Aspects of Organ Transplantation in Iran', (2004) 36 *Transplantation Proceedings*, 1241-1244

¹²⁴¹ Robert M.Veatch, 'Why Liberals Should Accept Financial Incentives For Organ Procurement', (2003) *Kennedy Institute of Ethics Journal* Vol.13, No.1, 19-36, p.24

In fact, Malaysia has already been giving out indirect incentives and privileges to regular blood donors. For instance, this group is eligible to receive free out-patient medical treatment at government hospitals, priority in receiving medical treatment, and first-class wards; in some hospitals, they even have their own service counter which provides them with services without having to queue¹²⁴². So, it would be highly desirable to simply extend this incentive to all registered organ donors who have pledged to contribute such precious gifts to others. However, once a registered potential organ donor withdraws his/her consent, these incentives must automatically cease too.

Hopefully, by agreeing to provide incentives, we would be able to attract more Malaysians to register as organ donors. The Department of Health and Human Services in the United States had offered 26 million dollars in grants to develop methods of increasing organ donation¹²⁴³. The US Senate recently passed the Organ Donation and Recovery Improvement Act 2004, which promoted donation by reimbursing organ donors for travel and subsistence expenses, besides establishing public education campaigns and funding hospital organ donation coordination programmes¹²⁴⁴. Likewise, the UK Health Departments actively encourage the reimbursement of live donors, particularly in renal failure cases, for their expenses. However, all reimbursements must be made by a proper authority, for example, by a primary care trust or hospital trust which is responsible for deciding whether (and how much) reimbursement should be given¹²⁴⁵.

Incentives are also essential for all the medical staff involved. In Malaysia, Tissue Organ Procurement (TOP) teams have been established in 16 Ministry of Health hospitals to

¹²⁴² 'Keistimewaan Penderma Darah', National Blood Centre Website, <http://www.pdn.gov.my.html>, viewed on 4 September 2009.

¹²⁴³ Shafer TJ, Davis KD, Holtzman SM, et al., 'Location of In-House Organ Procurement Organisation Staff in Level 1 Trauma Centres Increases Conversion of Potential Donors to Actual Donors', (2003), 75 *Transplantation*, 1330-1335.

¹²⁴⁴ *American College of Surgeons Bulletin*, December 2003, quoted in Ali Salim, George C. Velmahos, Carlos Brown, Howard Belzberg and Demetrios Demetriades, 'Aggressive Organ Donor Management Significantly Increases the Number of Organs Available for Transplantation', (2005) Volume 58, Number 5, *The Journal of TRAUMA Injury, Infection, and Critical Care*, 991-994.

¹²⁴⁵ Government Response to the House of Lords European Union Committee Report on 'Increasing the Supply of Donor Organs Within The European Union, 17th Report of Session 2007-08, September 2008, para 4.4, p.12

facilitate the management of cadaveric and tissue donations in these respective hospitals¹²⁴⁶. This is a good start, but it has not contributed much towards improving the organ shortage problem. According to Dr. Ghazali Ahmad, the effectiveness of such a system is influenced by the frequent reshuffles and changes involving the TOP team members and the nature of the system itself. Dr. Ghazali added that, because the system does not offer any incentives or penalties for the TOP team members involved, and because its implementation burdens the TOP team members directly with additional routines added to their usual daily duties, not many are therefore willing to seriously put the system into practice. Therefore, if we still want to maintain this TOP team, immediate steps must be taken to encourage them to undertake this responsibility sincerely. Besides that, close monitoring of the team's progress and achievements is crucial.

Every donation activity, including the rates of potential donor identification, number of referrals made, and numbers of approaches made for consent for donation, must be reported. With all this information, we will also be able to assess the current scenario while conducting more reviews to further improve the existing system and develop better performances within the TOP team itself and the public in general. So, to encourage the TOP team members to work harder towards realizing this effort, incentives in the form of job promotions, for instance, should be offered to those who are able to increase the number of solid organs procured¹²⁴⁷. However, if their progress is unsatisfactory and they fail to show interest in assisting others to donate organs, then certain penalties must also be introduced. For instance, they could be denied promotions or, alternatively, transferred to other departments¹²⁴⁸.

The same suggestion of adopting a policy of incentive and punishment was also recommended to the ICU staff at the Saudi Center of Organ Transplantation, to increase

¹²⁴⁶ Hooi LS and Lela Yasmin Mansor, 1st. Report of the National Transplant Registry 2004, NTR Publication, 2004, p.128

¹²⁴⁷ Interview with Dr. Ghazali Ahmad, Consultant and Head Department of Nephrology, Kuala Lumpur General Hospital, Malaysia on 12 February 2008

¹²⁴⁸ *Ibid*

awareness within the medical community¹²⁴⁹. However, at the same time, Saudi Arabia has been continuously organizing regular meetings for ICU doctors, hospital managers and nurses to keep them abreast of the religious and ethical aspects of organ donation, diagnosis of brain death, methodology in obtaining consent and methods of preserving the organs procured¹²⁵⁰. Spain has also been practising the same, as it pays bonuses to those involved in procurement activities for each successful donation achieved. And, although the bonuses are generally small, this is still one of the contributing factors to the success of the Spanish model¹²⁵¹. In Asia, it has been suggested that incentives be provided to the donor families as well as the medical doctors or the donor hospital to improve cadaveric kidney and liver transplant rates¹²⁵².

8.10 PROMOTING ORGAN DONATION THROUGH EDUCATION

Energetic education is another pathway leading to solutions to organ shortage problems¹²⁵³. Public and medical education both play a vital role¹²⁵⁴. A well-informed society is expected to have a different attitude and normally react more positively to organ donation and transplantation issues. Through education, societal awareness and the sense of familiarity with organ transplantation issues could be enhanced. The public must be brought to appreciate the complexity of organ transplantation and understand the role that they could play to help solve the organ shortage¹²⁵⁵. The problem of organ shortage also indicates that society is not aware that transplantation is a daily and urgent medical practice¹²⁵⁶. Therefore, frequent exposure to the consequences of organ shortage must be discussed as a common issue making it no longer something that is foreign or

¹²⁴⁹ Shaheen F.A.M, and Souqiyeh, M.Z, 'Increasing Organ Donation Rates From Muslim Donors : Lessons From A Successful Model', (2004) 36 *Transplantation Proceedings*, 1878-1880

¹²⁵⁰ Al-Khader A.A, and Shaheen, F. 'Strategies for Increasing Transplantation : The Saudi Experience', (1999) 31 *Transplantation Proceedings*, 3278

¹²⁵¹ Megan Crowley-Matoka and Margaret Lock, 'Organ Transplantation In A Globalised World, (2006) *Mortality*, Vol.11, No.2, 166-181, p.178

¹²⁵² Vathsala, A, 'Improving Cadaveric Organ Donation Rates in Kidney and Liver Transplantation in Asia', (2004) 36 *Transplantation Proceedings*, 1873-1875

¹²⁵³ Kennedy I, Sells R A, Daar A S, Guttman R, Hoffenberg R, Lock M, Radcliffe-Richards J and Tilney N, 'The Case for "Presumed Consent" in Organ Donation', (1998) *The Lancet*, Vol 351, May 30, 1650-1652, p.1650

¹²⁵⁴ Irene Carey and Karen Forbes , 'The Experiences of Donor Families in the Hospice', (2003) 17 *Palliative Medicine*, 241-247, p.241

¹²⁵⁵ Cantarovich.F, 'Education, A Chance to Modify Organ Shortage : A Different Message to Society', (2002) 34 *Transplantation Proceedings*, 2511-2512

¹²⁵⁶ *Ibid*

intimidating, particularly for grieving families¹²⁵⁷. Public education should also promote understanding of the concept of brain death, which is the legal definition of death, and impart the absence of religious prohibition of organ donation¹²⁵⁸. When people have a basic understanding of organ donation, it will at least be much easier to approach them and obtain their consent, as they will already comprehend the fact that cadaveric organs are a source of health to every member of society¹²⁵⁹ and, although they have lost someone dear to them, the lives of others still hang in the balance pending their response. In fact, better education and facilitated access could assist in making big decisions related to organ donations and will likely yield much better outcomes too¹²⁶⁰.

Education is powerful enough to make people understand that their willingness to donate their organs after death could possibly offer a chance of life and wellbeing for others and that we are currently trapped in a situation where we have more potential organ recipients than organ donors. Therefore, through education we could disseminate public policies as well as values sympathetic to the understanding of organ donation activities. Additionally, in our efforts to promote cadaveric organ donation, education can change people's attitudes towards this source of organs¹²⁶¹. They should be made to understand that the use of cadaveric organs is indirectly a potential guarantee of one's own future health, as acceptance of such use will enable transplantation treatment to be readily available to themselves, their families and everybody else, whenever necessary¹²⁶². The concept of bodily integrity over the cadaver should be replaced with the usefulness of re-using organs from the deceased party to help patients in need of these particular

¹²⁵⁷ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 137, p.31.

¹²⁵⁸ Vathsala,A, 'Improving Cadaveric Organ Donation Rates in Kidney and Liver Transplantation in Asia', (2004) 36 *Transplantation Proceedings*, 1873-1875

¹²⁵⁹ Cantarovich F, 'Influence of Socioeconomic and Ethical factors on People's Behaviour regarding the Use of cadaveric Organs', (2005) 37 *Transplantation Proceedings*, 539-542, p.539

¹²⁶⁰ Ashley Britton Christmas, Eric J. Mallico, Gary W. Burris, RN, Tyson A. Bogurt, RN Harry James Norton and Ronald F. Sing, 'A Paradigm Shift in The Approach to Families for Organ Donation: Honoring Patients' Wishes Versus Request For Permission in Patients With Department of Motor Vehicles Donor Designations', (2008) *The Journal of TRAUMA Injury, Infection, and Critical Care*, Volume 65, Number 5, pp.1507-1510, p.1510.

¹²⁶¹ Cantarovich, F, 'Improvement in Organ Shortage Through Education', (2002) Vol. 73, No.11 *Transplantation*, pp.1844-1846

¹²⁶² Cantarovich, F, 'Reducing the Organ Shortage by Education and by Fostering a Sense of Social Responsibility', (2003) 35 *Transplantation Proceedings*, 1153-1155.

organs¹²⁶³. They must realize that they too could possibly share this unique and non-replaceable source of health with others, particularly after death, by allowing the use of their or their relatives' organs after death. Education can send a societal message that organ donation is 'the right thing to do' while building a strong moral presumption in favour of organ donation¹²⁶⁴. So, once individuals have chosen to donate organs, they should find it very satisfying to know that their decision has been soundly made based on correct understanding, knowledge and a spirit of pure, voluntary altruism. Even organ recipients themselves claim to feel much better once they know that the organs they received were actually freely given by the donors and their families¹²⁶⁵.

Predominantly, education on organ donation issues are recommended for all children in school¹²⁶⁶ or, alternatively, for youngsters aged ten and above¹²⁶⁷. This early approach would make them committed to organ donation sooner, as an integral part of their obligations towards society. These educational programmes in schools are needed to teach them that cadaveric organs represent a unique and non-replaceable source of health and welfare to alleviate the current organ shortage facing humankind¹²⁶⁸. So, these discussions should be included in the school curriculum and adapted to suit each level and age of the child or adolescent¹²⁶⁹. Moreover, it is hoped that the future generation will be able to shoulder this problem of organ shortage should it later be inherited by them. It is believed that, once these children start thinking about organ donation, they can be expected to at least form their own opinion on it even though they are still young.¹²⁷⁰

¹²⁶³ Cantarovich, F, 'Improvement in Organ Shortage Through Education', (2002) Vol. 73, No.11 *Transplantation*, pp.1844-1846

¹²⁶⁴ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 7.2, p.15

¹²⁶⁵ *Ibid*, para 1.10, p.4

¹²⁶⁶ Paul Murphy from Leeds General Infirmary cited in the House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 142, p.31.

¹²⁶⁷ Cantarovich, F, 'Reducing the Organ Shortage by Education and by Fostering a Sense of Social Responsibility', (2003) 35 *Transplantation Proceedings*, 1153-1155.

¹²⁶⁸ Cantarovich.F, 'Education, A Chance to Modify Organ Shortage : A Different Message to Society', (2002) 34 *Transplantation Proceedings*, 2511-2512

¹²⁶⁹ Cantarovich, F, 'Reducing the Organ Shortage by Education and by Fostering a Sense of Social Responsibility', (2003) 35 *Transplantation Proceedings*, 1153-1155.

¹²⁷⁰ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 10.13, p.21

There was evidently a 53% increase in organ donation activities after “Donor Action Programs” were carried out in Europe by educating through the media, schools, colleges and other institutions, and appropriate training programs for hospital and ICU staff.¹²⁷¹

Education could also clear up all existing myths within society. For example, the public needs to be assured that, even if they have pledged to become organ donors, they will definitely receive the same treatment as non-donors should they become injured or sick, and that all efforts will be made to treat them and save their lives. They must also be made to understand that their organs will only be retrieved once they have been confirmed dead and there are no longer any signs of life or possibility of resuscitation. The medical team treating them will not be the same people later responsible for removing the donated organs. Misconceptions and myths - for instance, that old people cannot become organ donors - can be rectified and, of course, all this can only be achieved through proper education. This education programme must fulfil basic conditions including being permanent, motivated and implemented by fully committed, specially trained personnel¹²⁷².

Additionally, education should extend to health professionals such as physicians and nurses, as mentioned earlier in the chapter. At this juncture, they must recognize that organ donation is actually an integral part of end-of-life care for all suitable patients and therefore it must be well understood and presented to the public for their support and commitment. People should be encouraged to talk about organ donation within their families and to ensure that their relatives are also aware of their wish to donate organs. In Saudi Arabia, the Saudi Center of Organ Transplantation (SCOT) has attempted to improve awareness among the medical community about the importance of organ donation and transplantation by offering training courses, organizing visits to hospitals where donations take place, holding conferences, issuing publications (journals, booklets, pamphlets, posters and books), and including it within the curricula of medical schools

¹²⁷¹ Abouna, G.M, ‘Organ Shortage Crisis: Problems and Possible Solutions’, (2008) 40 *Transplantation Proceedings*, 34-38.

¹²⁷² Cantarovich, F, ‘Reducing the Organ Shortage by Education and by Fostering a Sense of Social Responsibility’, (2003) 35 *Transplantation Proceedings*, 1153-1155.

and postgraduate hospital training¹²⁷³. Some suggest using posters in GP surgeries, hospitals and libraries, as well as school discussions and medical television dramas¹²⁷⁴.

From the researcher's personal observation in Malaysia, death and organ donation issues are not commonly discussed by people openly. Most often, these issues are only brought up for the first time in a situation where an immediate decision needs to be taken. Without having much knowledge on such matters, one might easily feel offended and shocked and, as a result, deny consent to such 'intrusion' upon their loved ones. It is often difficult for families to discuss and reach decisions on these issues in such sudden situations. On the other hand, however, if sufficient information were provided, and organ donation issues gradually became a common issue, there might be more positive reactions and responses received from the public generally. However, above all, if people still do not consent to organ donation, even after much information has been provided and great efforts made to convince them, in the end we still need to respect their rights and decisions.

8.11 THE ROLE OF MEDIA

The role played by the media is absolutely essential as it is another very powerful tool for disseminating information to the public. The media is obviously capable of influencing and manipulating the minds and attitudes of society as its presentations of certain issues are very convincing¹²⁷⁵. The media is also the best way of providing sufficient accessible information to society at large, to enable people to make an informed choice. More publicity and discussion about organ donation must be made available, preferably before a person is faced with an incurable disease or imminent death¹²⁷⁶ as, by this point, they will already have a view about it and this will make it easier for them to decide. However, the number of donors will not simply increase as a result of simple press

¹²⁷³ Shaheen F.A.M, and Souqiyeh, M.Z, 'Increasing Organ Donation Rates From Muslim Donors : Lessons From A Successful Model', (2004) 36 *Transplantation Proceedings*, 1878-1880

¹²⁷⁴ Irene Carey and Karen Forbes, 'The Experiences of Donor Families in the Hospice', (2003) 17 *Palliative Medicine*, 241-247, p.245.

¹²⁷⁵ Eike-Henner W. Kluge, 'Improving Organ Retrieval Rates : Various Proposals and Their Ethical Validity', (2000) 8 *Health Care Analysis*, 275-295

¹²⁷⁶ Irene Carey and Karen Forbes, 'The Experiences of Donor Families in the Hospice', (2003) 17 *Palliative Medicine*, 241-247, p.245

coverage without a joint promotional effort from the medical community itself. Thus, the media can only achieve maximum effect with guidance and assistance from the medical community in highlighting certain aspects of organ transplantation and donation that it is truly essential the public comprehend¹²⁷⁷. This can easily be done by continually projecting news about transplantation activities, designing special television programmes, promoting transplantation, organizing public debates and scientific conferences, giving space to newspaper columnists and even organizing financial donations and marathons¹²⁷⁸. Moreover, cultural barriers to the acceptability of promoting cadaveric donations cannot possibly be overcome in a fortnight, as the process takes a lot of time and requires patience.

For this purpose, the mass media promotion of organ donation issues must be consistent and well-targeted on certain public concerns. The media should also be able to strike a balance on how to effectively promote an issue since, if the media is too enthusiastic towards organ transplantation activity, there is a risk that it could have an adverse effect on society¹²⁷⁹. Therefore according to Dr. P. Kalicinski, a transplant surgeon, the media, rather than approaching the medical community for sensational news worth reporting on, should instead shoulder a long-term responsibility to society by providing information and educational activities¹²⁸⁰. At the same time, the medical community should, in return, assist the media, particularly by supplying new, relevant material for publication and providing responsible specialist commentaries and advice to ensure that organ transplant-related topics are exposed in a more balanced and responsible manner¹²⁸¹. Another approach to influence and educate the media in organ donation issues is by holding periodic meetings between journalists, experts in communication and opinion leaders in transplantation¹²⁸². With the help of positive media publicity based on proper

¹²⁷⁷ Szmidt,J, Kalicinski,P, Zakowski, J, Jonas, A, Waleski,,P and Zagorski, S, 'Transplantation of Organs: Limitations and Possible Solutions', (2003) 35 *Transplantation Proceedings*, 1165.

¹²⁷⁸ Al-Khader A. ,and Shaheen,F 'Strategies for Increasing Transplantation : The Saudi Experience', (1999) 31 *Transplantation Proceedings*, 3278

¹²⁷⁹ Szmidt,J, Kalicinski,P, Zakowski, J, Jonas, A, Waleski,,P and Zagorski, S, 'Transplantation of Organs: Limitations and Possible Solutions', (2003) 35 *Transplantation Proceedings*, 1165.

¹²⁸⁰ *Ibid*

¹²⁸¹ *Ibid*

¹²⁸² Matesanz,R and Miranda,B, 'Organ Donation-The Role of The Media and of Public Opinion', (1996) 11 *Nephrol Dial Transplant* : Editorial Comments, 2127-2128

information, misconceptions on organ donation could be corrected and issues related to it could be discussed more openly while emphasizing and highlighting its positive and life-saving aspects. It is hoped that, sooner or later, the level of public awareness and understanding on organ donation matters might be raised and consequently more people would feel encouraged to consider it and hopefully join in as registered potential donors. Once the issue becomes something common within society, one could confidently and comfortably bring up the issue even in family conversations and indirectly let one's families know about one's personal views and wishes on the matter.

However, as much as the media can be useful in promoting an issue, it can also be potentially dangerous in adversely affecting organ donation¹²⁸³. It is powerful enough to jeopardize efforts to promote organ donation, particularly when it produces a surfeit of negative broadcasts on sensitive issues related to organ donation such as organ-trafficking, brain death, or fairness in accessing organ transplantation, which may adversely influence the public attitude to organ donation. Such negative broadcasts might even deteriorate the image of transplantation, causing more citizens to refuse to contribute and register as organ donors due to fear of misuse of the technology¹²⁸⁴. Adverse publicity can seriously reduce the supply by reducing the number of potential donors or causing relatives to withhold consent¹²⁸⁵. Equally, in incidences where polemical discussions on transplantation issues are raised by journalists merely to promote scandals or sensationalism, the mass media might highlight certain issues incorrectly and report wrong, imprecise answers¹²⁸⁶, even to the extent of providing false information about organ donations¹²⁸⁷. Although the best way of influencing public

¹²⁸³ *Ibid*

¹²⁸⁴ Matesanz, R, 'Organ Donation, Transplantation, and Mass Media', (2002) 35 *Transplantation Proceedings*, 987-989.

¹²⁸⁵ Kennedy I, Sells R A, Daar A S, Guttman R, Hoffenberg R, Lock M, Radcliffe-Richards J and Tilney N, 'The Case for "Presumed Consent" in Organ Donation', (1998) *The Lancet*, Vol 351, May 30, 1650-1652, p.1650

¹²⁸⁶ Cuzin B, Dubernard JM, 'Organ Shortage: The Solutions, Dordrecht: Kluwer; 1995, p.287 cited in R. Matesanz, 'Organ Donation, Transplantation, and Mass Media', (2002) 35 *Transplantation Proceedings*, 987-989

¹²⁸⁷ Susan E. Morgan, Michael T. Stephenson, Tyler R. Harrison, Walid A. Alifi and Shawn D. Long, 'Facts Versus "Feelings": How Rational Is The Decision To Become An Organ Donor?' (2008) 13 *J Health Psychol*, 644

opinion is through the media¹²⁸⁸, there is nevertheless no guarantee that its effects, either positive or negative, will last forever.

In Malaysia particularly, the media must give as much attention to organ donation campaigns as they give to blood donation campaigns. Were the matter to be discussed heavily by the media, people would feel more comfortable about discussing organ donation in family and work contexts, thereby helping others to appreciate the issue as well¹²⁸⁹. In the researcher's opinion, organ donation is not given as high a profile as blood donation. This is proved by the fact that NTR often organizes joint campaigns with the Blood Bank, as people do not respond to their promotions as much as they do to blood donation campaigns. With these joint campaigns, NTR is trying to encourage the crowd responding to blood donation campaigns to also consider the thought of donating their organs when they die. This negative response is actually a result of poor understanding of organ donation and organ shortage issues. However, if drastic measures are taken to improve the level of knowledge and awareness among Malaysians, there is a possibility of obtaining a more positive response, and NTR can start running their own campaigns without having to rely on other organizations.

8. 12 ORGAN DONATION CAMPAIGNS

Running campaigns to create public awareness on a particular issue is not an easy task. They must not only address different levels of society, with different cultures and beliefs, but must also be well-accepted by everybody. An effective campaign which focuses on the whole of society demands a high budget to make it possible to reach everybody. In the UK, Elisabeth Buggins, Chair of the Organ Donation Taskforce, confirmed that a generous budget of £4.5 million had been allocated solely for raising public awareness as part of the funding for implementation of the recommendations of the Organ Donation

¹²⁸⁸ Matesanz,R, 'Organ Donation, Transplantation, and Mass Media', (2002) 35 *Transplantation Proceedings*, 987-989.

¹²⁸⁹ Margareta A. Sanner, 'Promoting the Interdisciplinary Study of Death and Dying', (2006) *Mortality*, Vol.11, No.2, May, 133-150, p.148

Taskforce¹²⁹⁰. Although Malaysia might not need such a large amount due to its small size compared to the UK, undoubtedly a lot of money still needs to be invested for this purpose. For instance, in 2008, NTR was provided with RM 2 Million by the Government of Malaysia to create awareness of organ donation¹²⁹¹. It might perhaps seem to have cost a lot initially, with an additional need to set up the required infrastructure and facilities; however, if the right target is hit, we will actually save more money in the long run. This is because, when more organ donations take place, daily treatments such as dialysis, which are far more costly, will be reduced, as organ donations and transplantations are actually more cost-effective¹²⁹².

Malaysia needs to have organ donation campaigns targeted to achieve two main aims. First, the campaign must be informative so as to explain and promote organ donation, to make the general public understand what it is all about and what advantages accrue from it. Here, relevant information will be disseminated particularly on basic principles about organ donation, including on the criteria needed for one to become an organ donor, registration procedures involved, and introducing the NTR and its functions including highlighting the public's role in reducing organ shortage problems. These campaigns will aim to increase the number of people willing to come forward and register as potential organ donors. The Cystic Fibrosis Trust, UK, suggests that "it may be sensible to remind people that they are far more likely to need an organ than to be in a position to donate one" in order to raise public awareness of organ donation¹²⁹³.

The second part of the campaign must then tackle the challenge of how to ensure that all those registered potential organ donors do in fact eventually become actual organ donors. This part of the campaign will need to emphasize the importance of informing their

¹²⁹⁰ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 145, p.32.

¹²⁹¹ 'More Malaysians Pledge To Donate Their Organs, Malaysian Society of Transplantation, 9 February 2009, <http://www.mst.org.my/news/09022209nst.html>. Viewed on 28 August 2009.

¹²⁹² Aaron Spital, 'Should People Who Donate A Kidney To A Stranger Be Permitted To Choose Their Recipients? Views of The United States Public' (2003), *Transplantation*, Vol.76, No.8, 1252-1256, p.1252

¹²⁹³ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 138, p.31.

family members about their decision to donate organs¹²⁹⁴ and highlight the important role families should play, especially in giving support and respecting the wishes of their family members to donate organs. The British Medical Association has held similar campaigns which encouraged people to make known their wishes about donation¹²⁹⁵. In September 2008, the Welsh Assembly Government sponsored an organ donation awareness-raising campaign called “Donate Wales: Tell a Loved One” that was delivered and led by organ donation-related charities. This campaign promoted both the importance of telling our loved ones of our organ donation intentions and also the importance of coming forward and registering as an organ donor.

It is also worth maximizing the use of certain catchwords or phrases that simply reflect the basic idea of organ donation campaigns while also being touching and catchy enough for the public to easily remember. For instance, the NTR Malaysia has been using “the gift of life” phrase, which is very effective as it highlights the precious value of organ donation while emphasizing that, though valuable, it is still a gift for which no payments should be involved. Other catchphrases include “My decision today is my and my family’s health today”, “helping to live through organ donation”¹²⁹⁶, “live & then give” and “there is nothing simpler than becoming an organ donor - and nothing more important”¹²⁹⁷. The text of these phrases must be not only informational but also reassuring: organ donors need to know that they have actually made the right decision.

Another aspect that needs to be highlighted through these campaigns is the various religious stands on this issue. When comparing the Malay, Chinese and Indian populations, year after year, the statistics show that Malays are the least likely to register as organ donors although they are actually the majority race. It is important to

¹²⁹⁴ Schutt GR, ‘25 Years of Organ Donation : European Initiatives to Increase Organ Donation’, (2002) 34 *Transplantation Proceedings*, 2005-2006

¹²⁹⁵ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1:Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 140, p.31

¹²⁹⁶ Cantarovich.F, ‘Education, A Chance to Modify Organ Shortage : A Different Message to Society’, (2002) 34 *Transplantation Proceedings*, 2511-2512

¹²⁹⁷ Amitai Etzioni, ‘Organ Donation : A Communitarian Approach’, (2003) *Kennedy Institute of Ethics Journal*, Vol.13, No.1, 1-18, p9

understand the underlying factors causing Malays to resist organ donation. Religious beliefs may be playing a part, so it is crucial to highlight in these campaigns that Islam actually approves of and supports organ donation, particularly on the basis that it promotes brotherhood by saving other people's lives. It would also be beneficial to include a range of stakeholders such as non-governmental organisations, local faith groups and businesses to help promote and campaign on organ donation¹²⁹⁸. Should this effort be successful, organ donation issues will eventually be better comprehended and well-accepted by the Malaysians.

8.13 INCORPORATING RELIGIOUS AUTHORITY

There is a need to make explicit the various stances of the main religions practised in Malaysia, namely Islam, Buddhism, Hinduism and Christianity, on organ donation. By doing this, all existing doubts on whether a particular religion supports organ donation or not could be removed¹²⁹⁹. Besides that, local faith leaders must also realize that they have an important role in educating the public¹³⁰⁰ and increasing public engagement with organ donation, particularly by emphasizing the importance of saving other people's lives and openly discussing the issue from their respective religions' perspectives¹³⁰¹. The concept of brain death must also be explained and comprehended, especially according to the various faiths' perspective, as this issue is very much related to the process of organ donation being accepted and practised in society. Not only should all this essential information be included in posters and brochures and be projected in the electronic media, but there is also a need for the religious authorities to make themselves visible to and approachable by society. For this reason, we need to recognize the most influential

¹²⁹⁸ Government Response to the House of Lords European Union Committee Report on 'Increasing the Supply of Donor Organs Within The European Union, 17th Report of Session 2007-08, September 2008, para 2.10, p.6

¹²⁹⁹ The Potential Impact of an Opt Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 10.11, p.20

¹³⁰⁰ Daar,A,S, 'The Evolution of Organ Transplantation in The Middle East', (1999) 31 *Transplantation Proceedings*, 1070-1071, p.1071

¹³⁰¹ Al-Khader,A.A, and Shaheen,F, ' Strategies for increasing Transplantation : The Saudi Experience', (1999) 31 *Transplantation Proceedings*, 3278

religious people and organizations¹³⁰² and equip them with knowledge about organ donation, particularly on their religion's stand on the matter, as these are the people usually referred to by society for guidance and advice on their respective religions' views. Nonetheless, it is a sad fact that major religions do have disastrously low levels of factual knowledge about harvesting organs in end-of-life situations and are even uninformed about the scientific criteria employed to declare a person dead at the time of organ donation¹³⁰³.

Religious scholars and organizations are also urged to be present at and join in organ donation campaigns, to enable first-hand information and further clarification to be provided whenever necessary. Lee Lam Thye suggested that community leaders and doctors should take part in addressing the public through organ donation forums and debates in Malaysia;¹³⁰⁴ however, the researcher believes that religious scholars and representatives from government religious organizations are equally required to lend a helping hand as well. For Muslims in particular, information on organ donation and transplantation and the acceptance of the brain death concept could be included within the Islamic teachings during Friday and *Eid* Sermons or even within daily teachings held at mosques and prayer rooms. Therefore, certain cultural attitudes that have been rooted within society but are not in line with the true Islamic teachings must be corrected and changed.

Muslim scholars, too, are urged to be united in their view as we already have a fatwa made by the National Fatwa Council supporting organ donation in 1974. One contributing factor to organ shortage in Egypt was that the local religious authorities had failed to adopt a uniform position on accepting organ donation, which consequently

¹³⁰² Kececioglu,N, Tuncer,M, Yucetin, L, Akaydin,M, and Yakupoglu, G, 'Attitudes of Religious People in Turkey Regarding Organ Donation and Transplantation', (2000) 32 *Transplantation Proceedings*, 629-630

¹³⁰³ Joseph L. Verheijde, Mohamed Y. Rady and Joan L. McGregor, 'Negative Attitudes and Feelings of Well-Educated People About Organ Donation for Transplantation', (2007) 20 *European Society for Organ Transplantation*, 906-907

¹³⁰⁴ Annie Freeda Cruz, 'Spotlight: Saving Lives, One Pledge at a time', 2 June 2008, Malaysian Society of Transplantation, <http://www.mst.org.my/news/090209nst.html>, Viewed on 28 August 2009.

inhibited the development of cadaveric donations locally¹³⁰⁵. It would be regrettable if Muslims were to adhere too closely to their customs, causing confusion on matters that are actually allowed in Islam but not favoured by custom. Therefore, it is essential for religious authorities to help clarify and communicate issues relating to organ donation and the perspectives of their respective religions on it.

Similarly, we could also learn from the way in which Colorado's Donor Registry in the United States has worked with religious groups to promote organ donation. Its Donor Awareness Council's Religious Advisory Committee contributes by supplying newsletter bulletins, sample sermons, and educational materials and speakers, including organizing awareness programs such as the National Donor Sabbath (Colorado Donor Awareness Council 2002) within the community¹³⁰⁶. Let us refer again to the story of Teh Hui Yee: when the public learnt that her new heart was actually donated by a 15-year-old Malay boy who was also a Quranic scholar and whose parents were religious teachers, they were amazed. The boy's parents had also donated his lungs, liver, kidneys and corneas after receiving clearance from the state Mufti (religious leader)¹³⁰⁷. Once again the media highlighted the fact that a very religious Malay family was willing to help a Chinese girl. Eventually, after all these prominent reports in the media and, particularly, the public declaration of support by three state Muftis and the Director General of the Department of Islamic Development (JAKIM) himself on the issue, another four Malay donors came forward and donated multiple organs and tissues after brain death within a short space of time¹³⁰⁸. It could clearly be seen how this incident had created more confidence among Muslims in particular, in that organ donation and transplantation is allowed to be practised by Muslims. One can imagine how much stronger the effect would be were these influential Islamic Scholars and Muftis to declare themselves potential organ donors too! Without doubt, this would definitely encourage many more people to do the same, especially those from a similar faith group.

¹³⁰⁵ Daar, A.S, 'The Response to the Challenge of Organ Shortage in the Middle East Region : A Summary', (1997) 29 *Transplantation Proceedings*, 3215-3216

¹³⁰⁶ Amitai Etzioni, 'Organ Donation : A Communitarian Approach', (2003) *Kennedy Institute of Ethics Journal*, Vol.13, No.1, 1-18, p14

¹³⁰⁷ Lela Yasmin Mansor, Cadaveric and Tissue Donation, Fourth Report of the National Transplant Registry 2007, (NTR Publications, Kuala Lumpur, 2007)p.170

¹³⁰⁸ *Ibid*

8.14 CONTINUOUS GOVERNMENT SUPPORT

Besides the government taking initiatives to amend the law and provide the needed funding to promote organ donation at the national level, there is still a need for direct high-level political commitment to help champion the cause¹³⁰⁹. Local leaders are called upon to use their political influence to help promote and support organ donation in their respective communities¹³¹⁰. These political figures, however, still need to be strongly supported by certain consultant-level clinicians who would be able to foresee and comprehend further any particular needs and essentials related to organ donation and transplantation. These champions will then be responsible for developing and overseeing local policies needed to help maximize donations¹³¹¹, particularly by initiating related decisions in support of organ donation activities¹³¹². In Malaysia, the same view was shared by Dr. Lela Yasmin when she emphasized how important it is to have a certain political will to champion the cause¹³¹³. To be even more effective, these leaders must first pledge to donate their own organs and subsequently challenge others to follow their example¹³¹⁴. So, much more is expected from these community leaders than just a few speeches, as part of their contribution towards increasing organ donation rates within society.

The government is also urged to take measures to prevent more severe organ failure problems from occurring in the first place. By improving the health of the population, including promoting healthy lifestyles, access to primary medical care and

¹³⁰⁹ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1: Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 184, p.39.

¹³¹⁰ Daar, A.S, 'The Evolution of Organ Transplantation in The Middle East', (1999) 31 *Transplantation Proceedings*, 1070-1071

¹³¹¹ Government Response to the House of Lords European Union Committee Report on 'Increasing the Supply of Donor Organs Within The European Union, 17th Report of Session 2007-08, September 2008, para 3.7, p.9

¹³¹² Bernard Teo, 'Is The Adoption Of More Efficient Strategies Of Organ Procurement The Answer To Persistent Organ Shortage In Transplantation', (1992) *Bioethics*, Vol.6, Number 2, 113-131, p.120

¹³¹³ Interview with Dr. Lela Yasmin, Co-Chairperson, National Transplant Resource Centre on 14 January 2008 at the Ampang Hospital.

¹³¹⁴ Amitai Etzioni, 'Organ Donation : A Communitarian Approach', (2003) *Kennedy Institute of Ethics Journal* Vol.13, No.1, 1-18, pp.7-8

comprehensive preventive programs for common diseases, the number of individuals needing organs in the future can be reduced¹³¹⁵.

Support and medical care, comprehensive preventive programs and early detection of critical end-stage organ failure cases can obviously reduce the number of individuals needing organs in the future¹³¹⁶: as the saying goes, ‘prevention is better than cure’. Perhaps we could take an example from the Secretary of State for Health, UK, who had announced the “Putting Prevention First” programme in April 2008 as a national initiative to detect illnesses early, prevent later complications and plan care for those aged 40 to 74. Checks on this target group will assess a person’s risk of coronary heart disease, stroke, diabetes and kidney disease; the initiative is predicted to prevent at least 9,500 heart attacks and strokes a year and 4,000 people from developing diabetes, as well as detecting at least 25,000 cases of diabetes or kidney disease at an earlier stage, allowing people to be better managed and achieving better outcomes from treatment¹³¹⁷. All this is being done to reduce as far as possible the number of critical end-stage organ failures. Above all, organ donation activity must not be seen as part of the “Orphan Syndrome” where, although seen as something exotic, high-tech and an important solution to the organ shortage, it is not given the budgetary and political support it deserves¹³¹⁸.

8.15 MAINTAINING LIVING DONATIONS

While cadaveric donations are preferable, it is not, however, possible to totally cease using organs sourced from living donors, particularly in regenerative tissues such as blood and bone marrow¹³¹⁹, kidneys and livers. In recent years, a large expansion in donation practice has involved the use of living donors, including unrelated living donors,

¹³¹⁵ Joseph L. Verheijde, Mohamed Y. Rady and Joan L. McGregor, ‘Negative Attitudes and Feelings of Well-Educated People About Organ Donation for Transplantation’, (2007) 20 *European Society for Organ Transplantation*, 906-907

¹³¹⁶ *Ibid*

¹³¹⁷ Government Response to the House of Lords European Union Committee Report on ‘Increasing the Supply of Donor Organs Within The European Union, 17th Report of Session 2007-08, September 2008, para 6.5-6.6, p.18

¹³¹⁸ Daar, A.S, ‘The Evolution of Organ Transplantation in The Middle East’, (1999) 31 *Transplantation Proceedings*, 1070-1071, p.1071

¹³¹⁹ Shaun D. Pattinson, ‘*Medical Law and Ethics*’, (Sweet & Maxwell, London, 2006), p.440

and this is predicted to offer even greater potential in the future¹³²⁰. According to Dr Anthony Warrens from the British Transplantation Society, the outcome of a living donation is actually better than the outcome of any cadaveric donation, even if the living donor is not particularly well-matched¹³²¹. Therefore, it would be unjustifiable to totally ignore the possibilities of living organ donation because its assessment protocol and practice are vital¹³²².

Nevertheless, certain restrictions in its application are still necessary, especially in cases where there is no possibility of finding any matching cadaveric donors. It has been suggested by the Welsh Kidney Patients Association that living donations should not take place if they are subject to any financial gain or emotional feelings towards a relative¹³²³. However, in all cases, priority should still be given to those having blood relations as this would obviously benefit both donor and recipient. By allowing such a donation to take place, we would provide a more promising chance of survival not only to the recipient, but also to the donor, who is in most cases the carer or partner of the organ recipient¹³²⁴; thus, the donor would benefit from the improved quality of life of the recipient. This sharing of interests means that there is a greater risk of harm to an intimate family member in prohibiting him/her from donating than there is to an altruistic donor¹³²⁵.

Studies on people who have been donors suggest that the majority of them are very pleased that they became living donors and personally felt good about themselves¹³²⁶. However, it is undeniable that, in certain urgent cases, we should still provide room for

¹³²⁰ Arthur J. Matas and David E.R. Sutherland, 'The Importance of Innovative Efforts to Increase Organ Donation', (2005) October 5, Vol 294, No.13, 1691-1693.

¹³²¹ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1: Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 36, p.12.

¹³²² Rudge, C.J., 'Transplantation of Organs: Natural Limitations, Possible Solutions-A UK Perspective' (2003) 35 *Transplantation Proceedings* 1149-1150

¹³²³ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1: Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 226 p.47.

¹³²⁴ Glannon W and Ross LF, 'Do Genetic Relationships Create Moral Obligations in Organ Transplantation', (2002) 11 *Camb Q Healthc Ethics*, 153-159.

¹³²⁵ *Ibid*

¹³²⁶ Anthony Warrens, House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1: Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 222, p.46.

unrelated living organ donations too, provided that close monitoring and scrutinisation is maintained to ensure that there are no elements of trading, no commercial gain involved, no coercion and, most important of all, that the procedure is safe, will not cause unnecessary harm to the living donor, and is totally driven by the pure spirit of altruism. However, the researcher fully supports the stand of the British Kidney Patient Association that living donations, particularly in kidney cases, must only be considered as the last option, that is, after a period of time has elapsed but the required kidney is still unavailable¹³²⁷.

Nevertheless, in practice it must be extremely difficult to make judgements and strike a balance in allowing unrelated organ donation to take place, particularly because it is difficult to prove that no financial incentive has been sought or offered between the parties and the fact that actual physical harm is being inflicted on a donor who is otherwise healthy and well. Allowing this also puts him/her at risk of mortality, physical and psychological morbidity¹³²⁸ and long-term complications¹³²⁹. Nevertheless, we cannot deny the fact that, for the recipient, live donations are obviously healthier, as the timing of the transplant can be controlled to prevent the organs from degenerating outside the body¹³³⁰. So, there is always a need to balance between risks and benefits. Nevertheless, in all circumstances, maintaining a good safety record and good long-term results are always the main factors that make people feel more confident about become a living organ donor¹³³¹.

¹³²⁷ House of Lords European Union Committee 17th. Report of Session 2007-08, Increasing the Supply of Donor Organs within the European Union, Volume 1: Report, 2 July 2008, Authority of the House of Lords, London, The Stationary Office Limited, para 227, p.47.

¹³²⁸ Guideline of the Malaysian Medical Council, MMC Guideline 006/2006, Organ Transplantation, <http://mmc.gov.my/VI/doc/organ%20Transplantation.pdf>, viewed on 17 August 2009

¹³²⁹ Shaun D. Pattinson, *Medical Law And Ethics*, (Sweet & Maxwell, London, 2006), pp.440-441

¹³³⁰ Mason JK and Laurie GT, *Mason & McCall Smith's Law and Medical Ethics*, 7th. ed (Oxford University Press, Oxford, 2006), p.482

¹³³¹ Daar, A.S, 'The Response to the Challenge of Organ Shortage in the Middle East Region : A Summary', (1997) 29 *Transplantation Proceedings*, 3285-3216

CONCLUSION

There is much to be done to improve the organ shortage problem in Malaysia. Although it is impossible to implement all the above plans in one phase, the key is to take action on the very important things first and consistently improve the system. It is absolutely essential to first strengthen the organization of organ donation services including identifying potential organ donors while preparing the basic infrastructures needed to cater for the potential rise in organ donation. In short, improvements in identifying and referring potential donors, coordinating donors, and retrieving organs must be done simultaneously in a piecemeal fashion¹³³².

Meanwhile, the level of public awareness and understanding of donation issues must be raised specifically to the targeted group. An optimistic environment that is more accepting of organ donation must also be provided to improve the public attitude. This could be achieved by treating organ donation as a common issue and a routine choice offered as part of the hospital care provided. Malaysia must also aim to provide a transparent, systematic and quality organ donation system in the future while ensuring an increase in the availability of human organs, avoiding wastage of human organs and ensuring optimal use of existing natural resources. While certain standards must be achieved, continuous monitoring of the system's progress and development is crucial as well as providing continuous advice and support to all participating hospitals and registered donors alike. In short, combined cooperation by the lay public, medical community and religious institutions, as well as strong support from the government, is needed¹³³³ to enable all the suggestions above to be applied and, hopefully, our dream of solving the organ shortage problems in Malaysia will once and for all eventually come true.

¹³³² Emma Wilkinson, 'UK Government Plans Shake-Up of Organ Donation Services', (2008) *The Lancet*, vol.371, January 26, www.thelancet.com

¹³³³ Shaheen, F.A.M and Souqiyyeh, 'M.Z, Improving Transplantation Programs and Patient Care', (2005) *37 Transplantation Proceedings*, 2909-2910

CONCLUSION

Organ shortage is a serious problem that needs to be tackled effectively. In the context of Malaysia in particular, effective and drastic steps need to be taken immediately, as the waiting list of patients waiting for organs continues to grow and the demand for human organs seems to be endless. According to the Deputy Health Minister, Datuk Rosnah Abdul Rashid Shirlin, Malaysia currently has a total of 12,133 patients on the waiting list with 12,100 patients suffering from end-stage kidney failure, 23 with liver failure and the remaining 10 patients with severe heart and lung failure problems¹³³⁴.

The organ shortage problem in Malaysia is believed to be primarily caused by failure to identify registered potential donors and to ensure that they become actual donors later; there are also weaknesses in the administration of the existing procurement system. Other factors such as the misunderstanding of certain religious and cultural values, lack of awareness, and family objections undoubtedly contribute to the problem as well. However, having insufficient potential donors is not one of the causes of this problem as there is a positive, continuous increase in the number of people coming forward to register as potential organ donors. According to statistics from the National Transplant Resource Centre, up until 31st May 2011, Malaysia had a massive number of 169,224 registered organ donors¹³³⁵. Similarly, for the year 2010 alone, 13,164 people positively pledged themselves as registered organ donors¹³³⁶. So, the most important challenge faced by Malaysia now is to increase the number of actual donors, as statistics from the National Transplant Resource Centre also show that there were only 327 actual donors between 1976 and 31 May 2011¹³³⁷.

A few suggestions and solutions have been discussed and explained throughout the thesis but, in my opinion, the most important initial step to be taken is to focus and improve on the application of the existing opting-in system. Malaysia must maximise all possible efforts under this system, as it is already well-accepted by the public. By preserving the

¹³³⁴ Faridzwan Abdul Ghafar, '*Hanya 322 Derma Organ Sejak 1975*', Berita Harian, 5 June 2011, p.11

¹³³⁵ National Transplant Registry, <http://www.agiftoflife.gov.my/>, viewed on 1 June 2011

¹³³⁶ *Ibid*

¹³³⁷ *Ibid*

element of obtaining consent either from the donor him/herself, or at least from the next of kin, before any organ procurement procedure takes place, this actually helps to foster a more positive attitude towards organ donation within society, especially by allowing personal rights over human autonomy to prevail and respecting people's own preferred decisions, based on voluntary will and understanding. This results in a feeling of trust and confidence¹³³⁸ which can help organ donation to become a more popular practice.

Next, the power and influence of the family to object to and refuse organ donation should be legally removed. As this is a choice provided by section 2(2) (b) of the Human Tissues Act 1974, legal changes through amendments to the Act are required in order to remove such power from the family members. The organ procurement procedures currently in practice cannot proceed once any objection is made by the family members even though the donor, during his/her lifetime, had requested the removal of his/her organs¹³³⁹. So, even though one has already registered as an organ donor, and has received the organ donor card, the potential donor's organs still cannot be removed without the family's consent¹³⁴⁰. That is why it is highly recommended that registered organ donors inform and further convince their family members of their wish to become organ donors, so that the family is prepared and well aware of that fact. Such amendments would also secure the position of these registered organ donors, as their wishes would definitely prevail over any family objections.

Nevertheless, the role of the family and its influence are not to be totally set aside. It is suggested that they be given roles as witnesses in every organ donor registration process, particularly those involving their family members. So, whenever someone decides to register as an organ donor, he/she should be accompanied by two family members to act as witnesses. This additional administrative requirement would also indirectly allow the individual to discuss organ donation issues with his/her family at an earlier stage, and

¹³³⁸ The Potential Impact of an Opt-Out System for Organ Donation in the UK, An Independent Report from the Organ Donation Taskforce, January 2008, www.dh.gov.uk, para 8.2, p.17

¹³³⁹ Jade Chan, *Organ Donation A Gift of Life*, The Star online, 31 July 2009, <http://www.thestar.com.my>, viewed on 20 October 2010

¹³⁴⁰ *Ibid*

enable him/her to express such wishes openly. At the same time, respect for the family is still ensured and guarded.

Another possible short-term solution is to resort to the plentiful supply of organs available from road traffic accident victims. According to the Fourth Report of the National Transplant Registry 2007, 53% of brain-dead donors between 1997 and 2007 were involved in motor vehicle accidents¹³⁴¹, making road traffic accident victims a very promising source of much-needed organs. It would definitely make a big difference if more of these deceased victim's organs could be voluntarily donated to help save the lives of others, even though the deaths are, in themselves, devastating. Therefore, the best way to achieve this is by encouraging as many road users as possible to register as organ donors while renewing their driving license, applying for road insurance and during other procedures. No force of law is required in applying this; however, a wider range of opportunities for people to register as organ donors must be made available.

Additionally, it would be highly satisfactory were all the ambiguities found in the Human Tissues Act 1974 to be addressed immediately. Although Malaysia now has a supplementary policy which was introduced by the Ministry of Health, the policy will unfortunately not prevail if it is in conflict with any other existing law. Therefore, it is suggested that the content of the policy be incorporated into the amended Act, as only by having the force of law can it be more effective and efficient in application. Also, by incorporating the policy into the Act, both living and cadaver donation issues would be addressed comprehensively.

The introduction of incentive programmes for registered and actual organ donors respectively, is also essential. The incentive suggested should be in the form of providing free medical treatment and first-class ward facilities for all living organ donors. As for cadaver donors, these incentives should then be extended to their close family members,

¹³⁴¹ Lela Yasmin Mansor, *Cadaveric Organ and Tissue Donation*, 2007, NTR Publications, <http://www.mst.org.my/ntrSite/download/report2007/Chapter%208%20-%20Cadaveric%20Organ%20and%20Tissue%20Donation.pdf>, p.184, viewed on 22 August 2009

including their parents, spouse and children, for a certain period of time. It is suggested that, for the donor's children, such facilities should continue until they attain the age of majority and, for their spouse and parents, a duration of five to ten years seems reasonable. This type of incentive is relevant and suitable, especially as the cost of medical treatment and medication continues to increase. It would be a privilege for the living donors while cadaver donors could at least ensure that medical facilities were available for their beloved family members for a certain period of time.

Besides that, Malaysia must be equipped with an efficient database, directly connecting all government hospitals with the National Transplant Registry. This technology would enable the status of a person to be identified immediately, particularly whether he/she is a registered organ donor or not, simply by entering a national identification number which each and every Malaysian citizen has. Without such facilities and links, it is very unlikely that potential organ donors would be identified efficiently within a short period of time, resulting in precious organs being wasted due to lack of information and unnecessary delays.

To conclude, though organ shortage is a serious problem in Malaysia, I am positive that it can be gradually overcome, especially by implementing the above proposals immediately. Campaigning for more people to register as organ donors is necessary, but at the same time efforts must also be made to ensure that the number of actual donors also increases simultaneously. It is to be hoped that, by integrating the various proposals discussed above and implementing them as a whole, Malaysia might soon be proud of the large number of organs procured and the many lives saved, as not only would the position of potential registered organ donors be secured, but the procurement system itself would be more efficient and systematic. All this would contribute to helping Malaysia solve its long-standing organ shortage crisis.

QUESTIONNAIRE

A SOCIO LEGAL STUDY ON ORGAN SHORTAGE IN MALAYSIA

Instructions:

- Please circle/tick ONE answer or fill in the blanks whichever is necessary.
- All information provided is treated strictly confidential.

PART A: PERSONAL INFORMATION

A1) Age (on 1/1/2008):----- years
A2) Sex a. Male <input type="checkbox"/> b. Female <input type="checkbox"/>
A3) Race a. Malay <input type="checkbox"/> b.Chinese <input type="checkbox"/> c.India <input type="checkbox"/> d.Others <input type="checkbox"/>
A4) Religion a. Islam <input type="checkbox"/> b. Buddha <input type="checkbox"/> c. Hindu <input type="checkbox"/> d. Others <input type="checkbox"/>
A5) Highest Education Level a) <input type="checkbox"/> Primary School b) <input type="checkbox"/> Secondary School c) <input type="checkbox"/> College / University
A6) Which state are you from? <hr/>

B8) Are you aware of the Human Tissues Act 1974 that regulates organ donation matters in Malaysia?

a) Yes

b) No

PART C: YOUR INVOLVEMENT IN ORGAN DONATION MATTERS

C1) Are you a registered organ donor?

a) Yes

b) No

➤ **If your answer is Yes, please proceed to Section A**

➤ **If your answer is No, please proceed to Section B**

SECTION A: ORGAN DONORS

C2) How long have you been a registered organ donor?

C3) Why did you decide to become an organ donor?

a) To help save other people's life

b) I have experience of a loved one needing an organ

c) I have experience working with patients needing organs

d) I want to get honour and rewards

C4) What are the organs that you have agreed to donate?

C5) Who influenced your decision to become an organ donor?

a) Nobody

b) Family

c) Friends

d) Media

C6) Have you informed your family members about your decision to register as an organ donor?

a) Yes

b) No

a) Yes

b) No

D8) Malaysia is currently applying the “Opting In” system where organ donors would voluntarily register themselves as organ donors. Would you agree if this system is changed to the “opting out” system where everybody will automatically be a registered organ donor but are still allowed to opt out of the system if they disagree to become one.

a) Yes

b) No

c) Not sure

Thank you very much for your cooperation

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