

**POLICY OF LIVING DONORS: A STUDY OF QUALITY
OF LIFE OF KIDNEY DONORS IN MALAYSIA**

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ABSTRACT

According to the 2009 WHO Guiding Principles on Human Organ Transplantation Report of the Regional Meeting, Malaysia is still absent of living kidney donor registry up to 2012. Among the 15,399 patients on the waiting list of organ transplantation, 99 percent of them are kidney patients and thus the entire donation related promotions should be focused on kidney. Living donors are important source of the increasing hope of organ donations since the increase of deceased organ donations solely unavailable. But while living donation rates are on a rise in other countries, it is decreasing in the country which not only implies that there are plenty of work to do to reach a higher living donation rate, but also means that the potency of living donation in this country are huge and worth the efforts.

For this purpose, a survey to explore the quality of life of living kidney donors in Malaysia had been conducted by using a shorter version of the Short Form 36 (SF-36), i.e., the SF-12 of health survey, which was performed in 80 respondents out of 170 contacted living kidney donors of the donation time periods of 1990 to 2012. Analyzed data show the following three major conclusions: Firstly, the qualities of lives of living kidney donors have been improved after organ donations. Secondly, the living capabilities of the living kidney donors did not decrease but were maintained indicating that living donations should be encouraged and promoted among the Malaysian populations, and these data can be used to educate people in the country to have better confidences and stronger potencies to kidney donations. Thirdly, the results suggest that the enhancements and set-up of government policies and donor specific registry systems is necessary for helping living kidney donors to receive supports from the society, and well control their social activities after organ donations.

This research is strongly proposing a live donor kidney registry with policies to protect quality of life for living organ donor to be initiated and eventually implemented in Malaysia. This is urgently needed to protect living donors' lives and to promote increased numbers of future living donors in this country. An open, simple and easy means to use living kidney donor registry with policies to protect the quality of life of living donors could be a rapid and effective solution to the current problematic kidney donation situations.

ABSTRAK

Menurut WHO Prinsip Panduan Pemindahan Organ Manusia Laporan Mesyuarat Serantau 2009, Malaysia masih kekurangan penderma buah pinggang hidup yang berdaftar sehingga 2012. Antara 15,399 pesakit dalam senarai menunggu pemindahan organ, 99 peratus daripada mereka adalah pesakit buah pinggang dan dengan itu kesedaran dan tumpuan lebih diberikan pada pendermaan buah pinggang. Penderma hidup adalah sangat dinantikan pesakit buah pinggang akan tetapi masih tiada lagi kesedaran masyarakat untuk menderma lagi-lagi bilangan penderma yang ingin menderma selepas kematian semakin merosot. Malah kadar pendermaan hidup semakin meningkat di negara-negara lain di seluruh dunia, tapi ia semakin berkurangan di negara kita yang bukan sahaja menunjukkan bahawa kita perlu membetulkan strategi supaya kesedaran terhadap pendermaan organ di kalangan masyarakat bertambah bagi memastikan usaha ini dapat membantu kepada mereka yang memerlukan.

Bagi tujuan ini, satu kajian bagi menyelidik kualiti hidup penderma buah pinggang di Malaysia telah dijalankan dengan menggunakan boring selidik *Short Form 36* (SF-36), iaitu, SF-12, yang telah dilaksanakan pada 80 responden daripada 170 orang yang dihubungi yang telah menderma buah pinggang dalam tempoh masa 1990 hingga 2012. Melalui analisis data, tiga kesimpulan utama dibuat: Pertama, kualiti hidup penderma buah pinggang ketika hidup telah bertambah baik selepas pendermaan organ. Kedua, tahap keupayaan hidup penderma buah pinggang tidak merosot malah masih sihat dan baik menunjukkan bahawa penderma organ hidup perlu digalakkan dan dipromosikan di kalangan masyarakat, dan data ini boleh digunakan untuk memberi galakan kepada orang awam di negara ini supaya mempunyai kesedaran untuk menderma ketika masih hidup. Ketiga, keputusan mencadangkan bagi membaikpulih dasar-dasar kerajaan dan sistem pendaftaran penderma adalah disarankan untuk membantu penderma buah pinggang hidup bagi mendapat sokongan daripada masyarakat, dan juga dapat melakukan aktiviti sosial mereka walaupun selepas menderma organ.

Kajian ini mencadangkan supaya pendaftaran penderma buah pinggang hidup dengan dasar-dasar yang mampan bagi melindungi kualiti hidup penderma organ dilaksanakan di Malaysia. Ini amat diperlukan untuk melindungi kehidupan penderma yang masih hidup dan untuk menggalakkan peningkatan bilangan penderma yang masih hidup pada masa depan di negara ini. Justeru sistem pendaftaran penderma buah pinggang hidup yang mudah dan terbuka dengan membaikpulihkan dasar-dasar bagi melindungi kualiti hidup penderma hidup adalah salah satu kaedah yang cepat dan berkesan untuk mengatasi permasalahan semasa pendermaan buah pinggang.

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LIST OF ABBREVIATIONS

SF-36	Survey Form 36
SF-12	Survey Form 12
IQOLA	International Quality of Life Assessment
SPSS	Statistical Package for Social Sciences
ANOVA	Analysis of Variance
PPUM	Pusat Perubatan Universiti Malaya
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life
USA	United State of America
WHA	World Health Assembly
EULID	European Living Donation
ONT	Organizacion Nacional de Transplantes
UTAC	Unrelated Transplant Approval Committee
NKF	National Kidney Foundation

CHAPTER 1

INTRODUCTION TO STUDY

1.9 BACKGROUND OF STUDY

According to WHO (World Health Organization), (2009) Guiding Principles on Human Organ Transplantation Report of the Regional Meeting, Malaysia does not have a complete live donor registry (WHO, 2009). As of 2012, this remains unchanged. However, there are several remarkable improvements seen in the national policy for organ transplantation with the introduction of eligibility for unrelated living donation (Transplantation Unit MOH, 2011), though its effectiveness is highly questionable; of which will be discussed in the next chapter. Another great milestone of Malaysia's organ transplantation advancement is the success of the first ABO-Incompatible Kidney Transplantation in 1st & 2nd July, 2011 at a renowned private hospital in Kuala Lumpur (New Straits Times, August 2012).

Unfortunately, even with medical advancement and policy changes, it still does not guarantee the expected outcome of more kidney donations from living donors. Statistically, donation rate did increase over 100% compared to the last 10 years (12 donors in 2000), but the difference of 16 donors is less than patients that go on the waiting list in a month. As of May 31st, 2012, 15,399 patients were on the list of organ transplantation, of which 15,395 were kidney patients (Makmor et al., 2010). By June 30, the number increased to 15,420 (New Straits Times, August 2012). In just a month, 21 more patients were added to the list. It is a grave thought of kidney transplantation is the last option after all other medical means are exhausted.

The preferable treatment option for patients with end stage renal failure is kidney transplantation (Spital, 2005). However, there is a shortage of deceased donor kidneys for transplantation. In the Netherlands, average waiting times for deceased donor kidney transplantation have increased, and range from 2 years for patients with blood type AB to 5 years for patients with blood type O (Dutch Transplant Foundation). Patients waiting for a deceased donor kidney are dependent on dialysis treatment. Although dialysis is a lifesaving treatment, patients on dialysis are confronted with lowered quality of life (Lumsdaine et al., 2005; Ogutmen et al., 2006) and increased risk of morbidity and mortality: approximately 25% of all patients die while waiting for a transplant (Stichting Renine). Living kidney donation offers a realistic alternative to patients with end stage renal failure. In living kidney donation, a living donor donates one of his/her kidneys to the patient.

Donor risks for potential life threatening or severe complications are reported to be approximately 0.2% (Bia et al., 1995; Johnson et al., 1997), and donor mortality risks are estimated at 0.03% (Kasiske et al., 1996). The quality of life of living donors after donation is likely to return to pre-donation levels (Kok et al., 2006), and is reported to be even higher than that of the general population (Westlie et al., 1993; and Johnson et al., 1999). In the past, only the patients' close relatives were considered suitable as living donors for immunological reasons, but over the last decade non-related living donor kidneys have proved to give similar good outcomes (Terasaki et al., 1996; Terasaki et al., 1997). In addition, surgical techniques have improved (Kok et al., 2006), resulting in better outcomes for living kidney donors.

Although kidneys from non-related donor kidneys function equally well compared to kidneys from related donors but there is an increase of finding a suitable living donor. Spouses or partners, second-degree family members, friends etc., all became, in principle, eligible for living donation. It is found that spouses especially were enthusiastic about donating to their ill partner, because the emotional bond may be stronger and it provided both with the potential for a better quality of life (Thiel, 1997). A second development in the field of living kidney donation is kidney exchange donation (Klerk et al., 2005). Kidney exchange donation offers an opportunity for recipients who cannot receive directly from their original donor, due to blood type incompatibility or a positive cross-match. Incompatible donor-recipient couples can register for an exchange donation procedure, wherein patients exchange donors in order to receive a compatible kidney.

A third development is the growing acceptance of Samaritan kidney donors; people who are willing to donate a kidney to a patient they do not know (Jacobs et al., 2004). Over the last years, the reluctance concerning Samaritan donors seems to be decreasing: recently some transplant centers have started to publish their first results using Samaritan donation (Crowley and Switszer, 2005). The reluctance to accept the offers of Samaritan donors may not be based so much on medical grounds but more on psychological grounds; as for a long time, there were concerns that such donors might become mentally unstable (Henderson et al., 2003).

As living organ donation becomes more common, studying donor outcomes will become more important (Switzer and Twillman, 2000). The donor may benefit by improving survival chances and quality of life of his/her loved one. In addition, especially in case of partner-donations, there is a good chance that the donor's own quality of life will improve

as well. Morbidity and mortality are not the only variables of interest (Jacobs, 2000). Research indicates that donors may benefit in self-esteem (Fellner and Schwartz, 1971). Return to a satisfactory quality of life is also important (Gouge et al., 1990; Karrfelt et al., 1998; Johnson et al., 1999; Westlie et al., 1993; Smith and Province, 1986; Schover et al., 1997; and Toronyi et al., 1998).

When organ donation does not benefit the recipient, how donors adapt to loss, grief, and potential sense of futility or failure becomes important (Johnson et al., 1999; Smith et al., 1986; and Schover et al., 1997). In addition, studying donors longitudinally will be of benefit. Some interesting research questions include the following: How do donors feel if the graft is initially successful, but later rejected? What would happen if rejection occurs because of recipient noncompliance? How do family dynamics and relationships change because of living organ donation (Jacobs et al., 1998)? Although the rapid development of living kidney donation over the past decade represents a medical success story, one can identify several ethically and psychologically dilemmas, complications and their quality of life style.

1.10 RESEARCH QUESTIONS

The issues discussed tuned this research to investigate and in the end of the study, advocate solution to the questions listed below.

- i. Does Malaysia have enough policy that can guarantee the quality of life of living kidney donors?
- ii. Is the quality of life of living kidney donors in Malaysia at a good/excellent level?
- iii. Do the living kidney donors need support? (Clinics for Donors, Institutional Support and such)

1.11 PROBLEM STATEMENT

It has been argued that minimum sacrifice by living donors has contributed to maximum quality of life of a patient. However, little focus has been given to the quality of life of living donors. Living kidney donors often worried on their health status after they donate their kidney, and there is no adequate information and tools to help them to have better accesses to medical insurances, to receive financial aids from the government and local organizations, to share and receive information of organ donations, and to be organized for better performances.

Organ donation policies has been implemented in Malaysia since 1974, which include the Human Tissues Act of 1974, the National Transplant Registry of 2004, National Organ, the Tissue and Cell Transplantation Policy of 2007, and the Unrelated Living Organ Donation Guideline of 2011, etc. But most of them are about related organ donors and deceased

organ donors, and even the most recent one, the Unrelated Living Organ Donation Guideline of 2011 does not mention about live donor registry.

According to WHO, the rates of living donors are in a rise in different countries in the world and represent more than 40% of total organ donors in some countries due to the relatively adequate live donor registry systems established in those countries, which will be discussed in more details in Chapter Three. But similar situation did not happen in our country, and the organ donation rates are decreasing recently instead of increasing, which can be taken as a warning that we need to engage more and effective policies in our systems.

An open, simple and easy to use living donor registry with policies to protect the quality of life of living organ donor could be a rapid and effective solution to the current problematic situation. And thus, this thesis focuses on the quality of lifestyle of living donors in Malaysia, to promote the establishment and eventually implementation of living kidney donor registry, since 99% of patients on the waiting list belong to kidney patients, to benefit live organ donor and hopefully to encourage much higher number of live kidney donors in the near future.

1.12 OBJECTIVES

The objectives of this thesis are:

1. To provide the overview on the living kidney donors policy over the world
2. To analyze living kidney donors' quality of life in Malaysia.
3. To examine the idea of the establishment of institutions: living donors' registry and set-up clinic for donors
4. To provide recommendation on policies to protect the quality of life of living donors

1.5 SCOPE OF STUDY

The scope of this research will be focused on the living kidney donors in Malaysia that has donated their kidney at University Malaya Medical Centre (PPUM). It will emphasize on the quality of life of kidney donors after donating their organ. Among the aspects highlighted is the extent of their psychosocial and physical health after donating their kidneys. Moreover this research will also highlight the policy on the organ donation within and outside the country and to find out whether other country has done the policy on the quality of life of living kidney donors or otherwise. Besides, the study also gives recommendations on government strategies (policies) to be updated in the future to strengthen public confidence on physical and psychosocial health after donating which is the health is good and they will not hesitate to donate their organ in the future after knowing that the quality of life after donating is still good and excellent.

1.6 RESEARCH METHODOLOGY

1.6.1 PRIMARY DATA

This study is a quantitative research and the premier data collection is through questionnaire. At least 170 living kidney donors are called via phone and email to make an appointment for a free medical check-up in University Malaya Medical Centre (PPUM) as well as to answer the questions in the questionnaire given. For a period of 3 months only 80 people living kidney donors present for the medical check-up and subsequent responded to the questionnaire provided. Thus, the sample size used was 80 in that it represented the respondents from various demographic backgrounds.

1.6.2 SECONDARY DATA

The secondary data collection is through existing data obtained from the website of World Health Organization, website of Ministry of Health Malaysia, local and international journals, theses and related articles. These secondary data used to examine the quality of life of living kidney donors after donate their organs. With studies that have been conducted previously by researcher in other countries, it could strengthen the argument about the importance of the quality of life not only for the kidney recipients but also for the living kidney donors after the transplant occurred. In addition, secondary data is selected because it saves time and cost to obtain the required information.

1.6.3 QUESTIONNAIRE

The questionnaire for the living kidney donors is divided into two main sections which are Section A, B, C and D. Section A include a general question to know the background of the respondents such as gender, ethic, marital status, education achievement, monthly income before and after donation, employment status, age (current and at the time of donation) and much more. In Section B and C contains some very important question for this study which is the heart and the central part of this research. It includes the aims and the objectives which are related to the quality of life of living kidney donors in terms of the psychosocial and physical health. Some interesting research questions like the following: “How do donors feel if the graft is initially successful, but later rejected?” “What if rejection occurs because of recipient noncompliance?” and “How do family dynamics and relationships change as a result of living organ donation?” were asked and answered. Question in Section D is a direct question asks on the opinion of living donors on the institutional support after donation.

The study of quality of life of kidney donors longitudinally and cross-sectionally will be beneficial for the determination and identification of current kidney donors’ health situation and living condition in our country. A questionnaire protocol called the Short Form-36 (SF-36) Health Survey is a survey of patient health recommended by the International Quality of Life Assessment (IQOLA). The SF-36 is a measure of health status and is commonly used in health economics as a variable in the quality-adjusted life to determine the cost-effectiveness of a health treatment, which has been widely applied to the quality of life study of living organ donors in the world (de Groot, et al., 2012). The original SF-36

contains 36 questions and is more suitable for the evaluations of the health situations of living donors, and a shorter version of the SF-36 called SF-12 has been confirmed for its specific and practical evaluation purposes of the quality of life of living organ donor. The use of the Short Form Health Survey has been applied to the assess of changes in quality of life of living kidney donors successfully and yields meaningful data to translate the living donor condition to give helpful instructions to how to increase living donor rates (Mjoen et al., 2011).

In this purpose, researcher conducted a questionnaire survey among living kidney donors to investigate the quality of life of donors post kidney donation, since similar researches have not been conducted recently, or have only been conducted partially but not completely in our country. The focus of this research is on the quality of life of living kidney donors in terms of their psychosocial and physical health condition. The SF-12 is able to produce two summary scales originally developed from the SF-36 with considerable accuracy and with less respondent burden. And thus the SF-12 is an ideal choice as a short generic measurement providing adequate information on physical and mental health status of living donors.

1.6.4 DATA ANALYSIS

The Questionnaire Survey data based is elaborate and translate on the statistical data analysis results by using the world most popular statistical analytic software SPSS with its both functions (descriptive and inferential analysis) to process the survey data statistically, to reveal the current quality of life status of living donor in Malaysia scientifically and accurately. By using the descriptive statistics analysis, all the demographic part will be well-analyzed via the result of frequencies and percentages. Moreover the using of crosstabs analysis is quite important to see the effectiveness of quality of life in the correlation between ethnic (kidney donor) which are Malay, Chinese and Indian towards the relationship with their kidney recipient.

In addition, the use of inferential statistical comparison analysis which is the parametric tests (*T-Test* and *ANOVA*) is also important to investigate the differences between the current monthly income and income at the time of donation of the kidney donors, to discover is there any significant difference between the current employment status and employment status at the time of donation of kidney donors, to find out whether there is a significant difference between gender which is male and female towards the physical health problem of kidney donors for regular daily activities and much more.

Besides, the association analysis of parametric test which is *Pearson Product Moment* is used to treasure whether is there any correlation between the current healths of kidney donors towards the current health of kidney recipients and so forth. The results of this

analysis can give some conclusions about the factors that influence the quality of life of living kidney donors.

1.7 LIMITATION

In this study, there are several limitations that have been investigated. The primary limitation of the study is the time constraints whereby this research was planned to be executed over a semester of less than 20 weeks. The time is too fixed. Yet for this study has to make an appointment with the living kidney donors via phone call. So this automatically dragged the time on the data collection part which it took almost 3 months to reach the target of the sample size which is only 80 respondents from 170 phone calls that have been made up. Moreover to make an appointment is problematic the living kidney donors might be busy or staying outside Klang Valley and this will make them a bit harder to come to PPUM just to get the free medical check-up and to answer the questionnaire. In addition, there are so limited production of reports, journals and articles in Malaysia and this is also a hurdle to get the information required in this study. Therefore, researcher has to face the hardship just to ensure the validity and reliability of each data obtained through online

1.8 CHAPTERS OUTLINE

This study is divided into five main chapters. The first chapter begins with the introduction of the study which discusses the background of the study, research questions, objectives, scope of study, methodology and limitation of the study. The second chapter continues with a discussion of literatures on the quality of life for living kidney donors and also reviews the organ donation model that available in several countries in the world, followed by literature review of previous findings. Next, the third chapter discusses the policies of kidney donations at local and international level. In addition, in chapter three it is also emphasis on the live donor registry with policies on quality of life for living donor. Furthermore, chapter four analyzes the data from the questionnaire related to the quality of life for kidney donor. Last but not least, chapter five concludes with a discussion, summary of findings and recommendations to improve the existing policy of kidney donations in Malaysia and also for the use of future research indeed.

CHAPTER 2

QUALITY OF LIFE OF LIVING DONORS: A LITERATURE REVIEW

2.1 INTRODUCTION

For years, quality of life of living donors has been studied through establishment of donor registry in every nation. While the measures or indexes could differ from one country to another, it still follows the guideline set by WHOQOL standards (Gerald et al., 2011) and in addition, could be customized to suit the culture and demographics in practicing countries. For kidney transplantation, quality of life is measured for the purpose of, but not limited to, evaluating living donor's general physical, mental and emotional wellbeing; measuring the cost-effectiveness of the procedure and its financial consequences for donors; estimating future donations and monitoring and comparing disease burden.

In Malaysia, 80% of kidney transplantations are being sourced from living donors (Transplantation Unit MOH, 2011). Given the absence living donors who are not directly related (have no blood ties) to the patient since the introduction of the new policy, assume that at least for the past year to date, all living kidney donors are related to the recipients, thus stating the ineffectiveness of this policy. The current campaign in educating the public about kidney donation is emphasized only on cadaveric donation. Even with outstanding 29,500 new pledges as deceased donors achieved in 2011, it does not do much significance presently in helping patients that need urgent donations, as there is no foretelling of one's death and when the organ could be harvested. The current demand itself directly calls for more living donors, with primary preference given to deceased donors when available.

Thus, the current campaign on kidney donation should include both types of donation fairly. This could ensure that every potential donor is properly informed on current urgent needs and have the options for them to decide.

Based on the above facts, more efforts need to be done especially on acquiring more living donors, both related and unrelated. One of many ways would be to study past donations involving living donors through their present quality of life. Malaysia is greatly admired for its minimal fee for access to medical services and medications in public hospitals, but the absence of donor's registry which is a standard practice globally, is frowned upon, and is rather destructive to the positive perception towards the government. If we are to hope for positive growth in living donation rate, this is the best time to create a surveillance system while the number of living donors is still low. A crucial factor a potential donor would greatly consider before donating is if the act would have a negative impact on one's wellbeing after donation source. Such doubts and questions could be answered through the study of living donor's quality of life, which is one of the main objectives of this research.

This chapter is aimed to review the results and insights of recent studies made by international researchers on quality of life of living donor, and, the outcome of this literature review will be compared and discussed in later chapters and in later chapter discusses this review with our questionnaire results. This chapter would also discuss existing global organ donation models extracted from Amitai Etzioni's Organ Donation: A Communitarian Approach (Amitai, 2003), and compare them with the ones used in Malaysia while simultaneously ethically assessing if it could impact the donor's quality of life.

2.2 QUALITY OF LIFE BASED ON RECENT STUDIES

Kidney transplantation has become a normal surgical procedure worldwide as well as in Malaysia. It has been proven to have high survival and morbidity rate, and imposes low risk of medical complications post-transplantation. Nevertheless, studies show there are non-life-threatening physical conditions developed by donors in aftermath of donation. While the life changing experience has helped to boost self-esteem of most, there are some remote cases where donors suffer from minor to major psychological impact which could drastically deteriorate quality of life (Amitai, 2003).

This section reviews quality of life of living donors from various countries, cultures, types of donation, health care services and post-transplantation care. The source of SF-36 Surveys is used because it casts a global net, does not discriminate age group, sex, or cultural origin, and provides the most comprehensive results that align with the purpose of this study. The surveys were also done on matched demographics for comparison. This reveals useful insights and root causes that contribute to poor aspects of quality of life in each country, and in turn could generate more studies and researches in the future.

Source: The Quality of Life of Living Donors: Reviews of Short Form -36 surveys

The SF-36 covers 8 aspects: physical functioning, physical health, bodily pain, general health perception, vitality, social functioning, emotional health and general mental health. Based on the study, several countries stood out statistically. Norway, Canada, Scotland, Australia and India showed positive and comparable improvements in all 8 aspects of quality of life. More than 90% of donors were related. Though the differences were not significant than those from control group, each country (except India) offered universal

health care system, full reimbursement policy and good life insurance. In Norway however, 6% stated that donations do cause minor damage to their health to a certain extent. 24.5% had not been to follow-up sessions. This was due to the fact that 16.5% of them used personal expenses and 10.7% stated this as an economic burden. This finding proves that accessibility of excellent health care system, indiscriminating insurance policy and financial reimbursement play important roles in maintaining, if not improving, donor's quality of life. Indian donors have great post-transplantation care as attribute. All donors received early rehabilitations, attended follow-up routine regularly (4, 6, 8 and 12 months) and returned for work within average of 4 weeks. This finding also proves that quality post-transplantation care highly contributes to donor's quality of life.

In the study conducted at Santa Casa of Sao Paulo Hospital, Brazil on related and unrelated kidney donors (92.7% and 7.2% respectively), results show that donors scored comparatively higher in 7 of the scales with negligible difference on physical functioning. The significant spike of improvement could be seen in social functioning and emotional state than that of the control group. However, on a specific assessment made on quality of life of donors whose recipients suffered loss of graft and death after transplantation, the results showed lower scores in 7 scales with distinct deterioration in mental health. This strongly proves that the health condition of recipients have substantial consequences to a donor's quality of life.

There are noticeable similarities of deterioration in the same 3 aspects from a few countries. They are physical functioning, physical role limitation, and bodily pain. The results are consistent in Italy, China, Turkey and Brazil (Minas Gerais), in which donors suffer from various physical pains and problems such as back pain. These are actually believed to be

the common side effects of kidney donations, but the real cause remains uncertain and sufferers appear to be random. Overall score on social functioning are mostly improved in most donors, as the act itself proved to boost self-esteem. But in United Kingdom, the survey results somehow declined in every scale when compared between pre-donation and post-donation's quality of life. This raises a huge question mark as 66% scored significantly lower than pre-donation stage. However, 83% show willingness to donate again if given the opportunity.

Other than the 3 aspects of physical deteriorations for Chinese donors, other finding worth noting is that 28.6% of related donors were ill-informed and were not aware of the benefits and risks of living kidney donation. China's policy in obtaining organ mainly relies on its conscription towards executed prisoners, which derives more than 90% of transplants (Alex et al., 2010). Since unrelated living donation is prohibited, the remaining donations are from related and cadaver donors. Based on this information, a conclusion could be made that China lacks emphasis in preparing and educating living donors thoroughly. Fortunately, none of the donors regretted their decisions nor experienced anxiety or depression, but 22% admitted that the donation to be an extreme financial burden. While willingness to donate to relatives is indeed an altruistic deed, but emotional relations should not be taken advantage of and does not make education any less important in the eyes of authorities. Crucial information such as financial preparedness should be one of the main factors considered by every related and non-related living donor, as this could affect their quality of life.

Of all results of quality of life, the worst could be seen from "donors" in Iran. A concentrated study for vendors was done and each of them scored significantly lower than

the control group in every scale. This means that post-donation, vendors did not enjoy physical and general wellbeing, faced hardships in running daily activities, had lower stamina, suffered from emotional instability and depression, and had lower self-esteem. Around 80% Iranian vendors could not afford to go for follow-up visits due to poverty, let alone tend to other medical cares. Other serious implication of vending was 65% of them could not find a steady feed while their quality of life was excessively affected. Vending do not only deteriorates one's quality of life, it violates ethical and religious values to its fundamental level (Amitai, 2003). Even though Malaysia prohibits buying and selling organs, this is nonetheless an important study to reiterate the negative consequences it portrays on organ donation and donor's quality of life.

2.3 ETHICAL VIEW ON ORGAN DONATION MODELS, CURRENT PRACTICE IN MALAYSIA AND THEIR IMPLICATIONS.

Soaring demands of organs to treat terminal illnesses have led many countries to implementing new guidelines, introducing new act and policies, and even easing previous restrictions made previously in obtaining organs. While every organ donation model has its own merits towards achieving the goal of meeting the organ demands, just like every action, it has its consequences.

2.3.1 CONSCRIPTION

Like military conscription, this model suggests that organ donation is an “obligation”, but towards prisoners. This has been practiced in China since 1984 which is condemned by the entire world. This model extracts organs from deceased executed prisoners (Alex et al., 2010) which according to China, they had given their full consent. This raises a lot of suspicions and even though a lot of investigations and verifications was attempted to be conducted on the case, China seems reluctant to cooperate and do not try to justify its actions besides some profound allegations. The problem with this approach is in its ethics and moral grounds. Since there was never such policy or guideline written specifically for prison donors and that, it is masked under spiritual cover, there are a lot of grey areas and it could only speculate how this approach could easily be manipulated.

One question is enough to doubt the approach. “If prisoners had given their full consent to donating their organs, why hasn’t it been enforced the same to the entire China population?” This could instantly relief the huge demand in the country. Instead, the

procedure is done between brick walls with discretion even towards the donors' families. Families of deceased prison donors usually find the prisoners' bodies were already cremated after they were put to death. This donation model should never be practiced in Malaysia as there seems to be no transparency and is discriminating towards prisoners.

2.3.2 PRESUMED CONSENT

The presumed consent approach automatically assumes that every citizen has agreed to donate their organs upon death unless they explicitly opt out (Amitai, 2003). Opt out approach is carried out in different ways; by choosing through passport application, tax return or other registered documents. Although the method gives the option not to donate, it pushes the responsibility to the population to make sure that their organs are not harvested upon death instead of inviting them politely to donate. It somehow oversteps and manipulates basic human rights, when one should be given liberty to give based on pure intentions, not donation that's (had been pre decided) decided for them.

Singapore practices this model, and as of 2009, the age-limit of deceased organ donation under presumed consent has been removed (WHO, 2009). This could lead to further manipulation of organs to be used for medical research or even transferred abroad to unknown recipients, or worse, sold for profit. It is too presumptuous, coercive, manipulative, and showing disrespects of one's beliefs in basis of faiths and opinions on donations. Furthermore, it is highly inappropriate of a government to simply decide on such endeavor for its people and dismiss itself the responsibility to properly educate them. If every unrelated living donor is required to be capable of comprehending the benefits and risks of organ donation, why is a potential deceased donor denied of such education? What

if a potential deceased donor under presumed consent is illiterate and does not own a car, or mentally challenged? Who speaks for their rights?

This approach speaks of ulterior motives from the way it is conducted through tax returns and renewal of driving license, instead of through their identity card, birth certificate, or medical record. It imposes high risk of negligent from the government to allocate funds in properly educating its people and in consequence, the public could totally be ignorant to the fact that such policy exists and they have the choice to opt out through certain documents. There is also the question of visibility of the opt-out option on the said documents, as to how much emphasis on organ donation is given, or would it only materialize as a footnote that's easily overlooked?

This model has been considered to be applied in Malaysia, but had never been realized as to date. It is true that applying this model would make a lot of organs available overnight, but it would not be a truly justified cause and tarnish the altruism nature of organ donation.

2.3.3 REQUIRED RESPONSE

This policy means that a competent person is required to make a “mandated” choice by giving an explicit answer about organ donation. This is by far the least coercive obligatory model, as it still respects the autonomy of one’s body and rights. The risk that entails this approach is the possibility of losing potential donors when asked at inappropriate time, added by lack of useful information. Someone lining up for license renewal and in a rush to get back to work is not ready for bombardment of new information, and these people would simply utter a flat “No” without even considering. A demand of an explicit answer also displays a lack of patience and interests in properly sending the right message.

However, a spinoff of this method coupled with enthusiastic and sincere educational team and campaign could show some results. Instead of required or mandatory response, this could be a “required opinion” or “required survey” spread through formal forms that entitles itself at the whole last page. The details of this kind of forms would be some brief statistics or facts that touch on religious and ethical views, and the urgent need of patients that are on the waiting lists, types of donation along with the safety of living organ transplantation. Then, some additional questions are asked; if they would consider the possibility to help either as deceased or living donors? It is also paramount to suggest that there will be no obligation to donate and that the intention of the form is simply to make sure every literate person knows about the issue and have the options to help. An interested individual would then fill out his contact information, and this will be followed up by personal invitation or meet up with the education or transplantation team to provide the fullest details. This spinoff approach makes sure the potentials are open-minded to receive

important information on organ donation, respects one's opinion and individual rights and concentrate resources on quality leads.

2.3.4 COMMODIFICATION

The word commodification derives from “commodity” which means “one that is subjected to ready exchange or exploitation within a market”. In other words, it is the act of buying and selling organs. While most countries have publicly prohibited this model and have it written on their national organ transplantation policy, along with severe punishment and fine for perpetrators, it does not hinder the black market of organ donation to exist. This method could be perceived as an economist method. It strips a vendor of all basic rights and protection, as the buyer is only interested in paying and retrieving the organ. There are no invested interests in their wellbeing post-donation and definitely no quality medical treatment or drugs used during the harvest. This organ would then be transported across the borders to its recipient. The act of justifying paying for organs has opened a lot of business opportunities for brokers and agent who act as middlemen and seekers of potential vendors and they would carry out the screening, blood test, persuading and convincing all the way through transporting and evading the detection of authorities.

Medical tourism is often manipulated in association of organ trafficking. While medical tourism is practiced and allowed in Malaysia, an enforced policy should exclude organ transplantation for medical tourism and strongly prohibited for all foreigners. This immediately prevents any sorts of exploitations from outsiders and brokers taking advantage of our medical system, people and our image as a country that gives high regard to moral and religious values. A great example could be seen from Philippines. In 2007,

there were approximately 1000 organ transplantations took place (WHO, 2009). By 2008, Philippines closed its doors and foreigners were no longer allowed to receive organ donation from non-related Filipino donors. The action proved to be effective, as end of 2008, the total number of transplantation decreased to about 650. Malaysia could follow this example as we are still far way in meeting the current organ demand.

2.3.5 COMPENSATION

While various views somehow mix compensation with commodification approach (Amitai, 2003), they really in fundamental of two different methods. Compensation or sometimes called reimbursement is a way to relief some burdens which associated with, but not limited to financial aid. The differences are very important to note as one could easily reject compensation method without giving it much consideration just because it could involve some financial incentives. The fact is, this method is extended in various ways and it may as well not be in financial form. The distinct contrast is in intention. The vendor and buyer act puts monetary value on the organ, with a vendor expecting to be paid. The transaction is considered as a business and vendor takes full responsibility to their quality of life. Whereas in compensation, the intention is still pure and based on altruism, and a donor does not initially make the decision just to get a small compensation. Besides, a donor does not determine the incentive given to them, but rather it's a policy change in line to promote organ donation. Tarnishing or doubting one's pure intention by treating compensation is the same as vending could be said as offensive if not insulting.

A few good examples could be seen from varying countries. Iran for instance tackled its widespread in organ trafficking by giving financial incentives to its living donors (Alex et

al., 2010). This is a huge learning curve for Iran from legitimizing free kidney sale in 2006, which resulted in poor quality of life to its living donors. However, the compensation policy proved to work as it did reduce organ commercialization and helped boost Iran to third place globally in living kidney donation rates. Another drastic improvement would be from Saudi Arabia, which gives monetary reward of USD 13,300 plus life-time medical care to living donors. The sole purpose is to stop its citizens from going abroad to receive organ transplants. However it is imperative to note that such compensation measures have its valid and urgent reasons. For Saudi Arabia, before the introduction of the new policy, organ donation was strictly between related donors and recipients. This forced some capable patients to seek donors from abroad. The most probable cause for the drastic monetary reward could be religious, so as to prevent the source of organs coming from non-Muslims coupled with unforeseen medical complications if the transplantations was done abroad. This policy could be transient, and when the demand has subsided, it could as well be abolished.

As mentioned earlier, adopting this method is highly based on its needs. The current need in Malaysia is over 15,000 patients on the waiting list compared to average of 100 transplantations achieved in a year. In the new policy of unrelated living donations, it is stated that all hospital fees pertaining to the organ procurement will be waived and donors are entitled to free first class ward admission (Transplantation Unit MOH, 2011). This is a huge positive encouragement towards the right direction in living donation rate.

2.4 CONCLUSION

This review concludes that organ donation imposes low health risk and possesses high survival and morbidity rate. The donor mortality for kidney donation in Malaysia is 3.1 deaths in 10,000 donations, which is around 99.7% (WHO, 2009). While it seems that survival rate is high, even a death of a donor is considered a tragedy. Malaysia's medical practitioners should keep working towards achievable 100% like China (WHO, 2009). It could also be concluded that setting up a national donor's registry is imperative like never before, reiterating the acknowledgement made in 2009's WHO Regional Meeting. Installing a surveillance system is the key towards noticing a policy's flaws and celebrating organ transplantation successes. This is done through studying a living donor's quality of life. A donor's quality of life is very telling and unbiased, and the findings could contain answers as to how the government and policy maker could improve our policy and persuade more living donors to come forward. Current living donors would also be willing to participate in the efforts of saving lives if their wellbeing is looked after. A real life testimony and invitation from a living organ donor could move a lot of potential donors and bears strong psychological appeal.

Of all scales in quality of life, three of them are the ones with most occurrences suffered by living donors. They are physical functioning, physical limitation (role) and bodily pain. The cause is relatively unknown and sufferers appear to be random, but the same physical deteriorations were consistent with other studies. This has somehow known to be the common side effects of kidney donation. Assuming that the medical service in each of the country where the survey was conducted was of excellence, a hypothesis could be made that this was due to drug intolerance for certain individuals.

For living donors that showed positive or improved quality of life, the reason for success comes from universal health care system, access to good life insurance policy, and with some countries practicing reimbursement policy such as Norway. In addition, excellence in post-operative care and follow-up visits still helped improving quality of life even with the absence of insurance policy and reimbursement. Mental health could be disturbed especially when the relationships between donor and recipient became sour, or recipients died due to organ rejection. Anxiety and depression usually comes from financial burden coupled with physical deterioration.

Malaysia is seen as a little behind in organ transplantation policy. While this is technically true, this is still not a race among nations. The most important thing to be grateful of is that Malaysians fortunate to live in a country that puts high regard and respects on everyone's religious beliefs and moral grounds, and if anything, they being too careful in drafting the policies. So far the people have made all the right moves by banning organ trade, allowing unrelated living donation with preferential given to relatives, promoting deceased donations and waiving all medical costs from donors. A little bit of push is all that is needed. If the government set up a donor's registry, holding sincere campaigns for all types of donation with collaborations from real living donors, practice "required opinion" that is backed up by group meetings of interested potential donors held by transplantation team, and on the back-end, the system offers some type of medical benefit compensation, this could be a real whistleblower towards perfecting our own model.

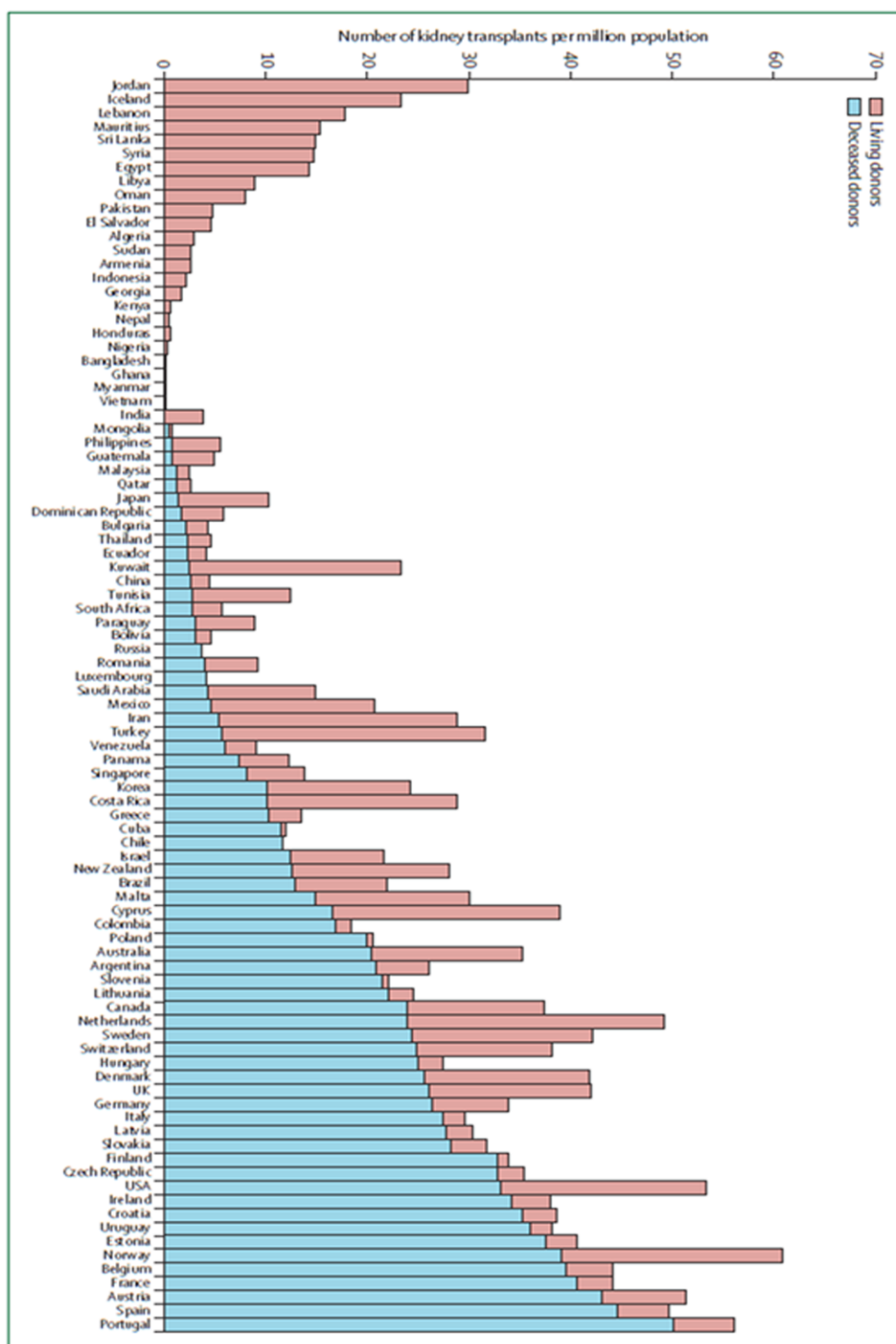
CHAPTER 3

POLICIES FOR LIVING KIDNEY DONORS: LOCAL AND INTERNATIONAL

3.1 INTRODUCTION

Approximately 100,000 patients worldwide undergo organ transplantation annually, but many other patients remain on waiting lists according to the WHO (Delmonico et al., 2011). Transplantation rates vary substantially across countries. Governments of different countries are required to systematically address the needs of their countries according to a legal framework. Medical strategies to prevent end-stage organ failure must also be implemented. A new paradigm of national self-sufficiency is needed. Each country or region should strive to provide a sufficient number of organs from within its own population, guided by WHO ethics principles. One of the important policies from governments is the donor registry system which is proven as a critical policy for those countries with predominant organ donation regulations. Until 2011, the top twelve countries which possessed the highest organ transplantation rates reported by the WHO are as follows: Portugal, Spain, Austria, France, Belgium, Norway, Estonia, Uruguay, Croatia, Ireland, USA and Czech Republic (**Figure 3.1**) (Delmonico et al., 2011). The common features of these twelve countries are that they all have donor registry systems and accept organs from both living and deceased donors. The donor registry systems are set up as either voluntary or mandatory depending on the specific country. Most of the countries have established voluntary donor registries, but others like the State of Victoria in Australia require mandatory donor registry (Paxman, 2012).

Figure 3.1 Numbers of Kidney Transplantation from Living and Deceased Donors for countries with Any Registered Activity at the Global Observatory on Donation and Transplantation (2009)



Organ transplantation is different from other medical services because its practice does not rely solely on professional expertise. Other crucial factors are the medical suitability of donors and recipients and the willingness of living donors or deceased donors' families to donate. According to the 63rd WHA Resolution, governments have a responsibility to ensure appropriate access to safe and ethical transplantation with special attention to maximizing donation from deceased donors and to protecting the health and welfare of living donors. Organ specific registries of transplant recipients and donors should be assembled to enable annual review of data. Legislation should be created to establish national frameworks for overseeing programs.

In Malaysia, people are urgently seeking for higher number of organ donors especially kidney donors, but it has not been seen as a remarkable change since the 2011 new policy of unrelated donor donation guideline was introduced. The acceptance of unrelated donors will enlarge the donor sources comprehensively because almost 50% of kidney donors in the Western Pacific Region are living unrelated donors and the number of heart and liver transplants in the region is also increasing (WHO, 2009). But people in Malaysia are not aware of the importance of unrelated donor sources due to different factors, such as education backgrounds, religious and moral reasons. Malaysia is a country composed of populations with multiple cultures and religions, and it is not possible to depend on the regulation of existing policies to fit to different ethnic needs.

In addition, as mentioned in Chapter Two, Malaysia's organ donation models are limited to only two out of the five possible models of the world standard due to the religious and society features. As a consequence, the government bears a responsibility to improve its policies in order to enhance possible donor sources under such limiting conditions. For this

reason, it is strongly proposing live donor registry with policies on quality of life of living donors, especially for kidney donors, to be established in Malaysia in this chapter.

3.2 ORGAN DONATION POLICIES IN DIFFERENT COUNTRIES INCLUDING MALAYSIA

Organ donation policies vary in the top twelve organ donation countries, but common policies that are shared among them is the well-established donor registry system with policies on quality of life of living donors, which has been proven to be effective in these countries. It is herein comparing the donation policies from these countries with those of Malaysia.

3.2.1 ORGAN DONATION POLICIES IN SPAIN

Most of the top twelve organ donation countries are European countries. The European Living Donation (EULID) follows the WHO guidelines and suggests that the registration practices should include three levels: 1)The basic level: it allows watching the living donation activity and the percentage of donor-recipient relationship. 2)The advanced level: it collects clinical data both prior to donation and afterward to determine the complications and to establish correlations. 3) An excellence level: it evaluates the quality of the entire living donation program, donor quality of life and satisfaction, as well as aspects about management, policies, and legislation (Manyalich et al., 2009).

As an example of the top European donation countries, Spain is one of the leading countries for numbers of organ donation with 34 donors per million inhabitants. Spanish officials

have implemented a policy of voluntary registry with presumed consent to boost the number of donors successfully (Spooner, 2003). The Spanish government created the Organización Nacional de Trasplantes (ONT), a network of transplant coordinators in intensive care units across the country. ONT professionals identify potential organ donors by closely monitoring emergency departments and tactfully discussing the donation process with families of the deceased. In addition, the policies and practice of donor quality of life are ongoing in Spain currently. These are considered important factors for the country's higher donation rate.

3.2.2 ORGAN DONATION POLICIES IN THE USA

More than 30,000 cases of organ transplantation are performed annually in the US which represents about 1/3 of the world totals. Donation policies are more complex in the US than other countries due to the differences among states. The US government and transplantation organization are dedicated to the quality of the entire living donation program and donor quality of life and satisfaction. As the consequence, even though the US officials implement voluntary registry without presumed consent since the presumed consent was abandoned in 2006 (Orentlicher, 2009), the US organ donation rate still reaches 26 donors per million inhabitants currently.

To further increase the number of donor sources, some states in the US have argued that prisoners should voluntarily consent to donor registration just as they can consent to medical procedures recently. A program in the state of Arizona has encouraged inmates to voluntarily sign up to donate their heart and other organs since 2008. There is no US law against prisoner organ donation; however, the transplant community has discouraged the

use of prisoner's organs since the early 1990s due to concern over prisons' high-risk environment for infectious diseases. Nevertheless, modern testing advances to safely rule out infectious disease and ensuring that there are no incentives offered to participants should make prisoner registration possible (O'Reilly, 2007).

3.2.3 ORGAN DONATION POLICIES IN MALAYSIA

Living donor registry has been considered one of the critical factors in the top twelve donation countries, which has been implemented in Malaysia as well. However, the current situation in Malaysia is much less applaudable. The organ donation rate is only 0.64 donors per million inhabitants in our country, which remains the lowest in the world (Transplantation Unit MHO, 2011). On the other hand, it is estimated that as of May 31st, 2012, 15,399 patients with end-staged organ diseases are waiting for available organs. These facts underscore a grim and urgent situation for donor donations especially kidney donations in Malaysia.

In the past years, several important policies were implemented in this country: the national transplant registry of 2004; the National Organ, Tissue and Cell Transplantation Policy of 2007; and the Unrelated Living Donor Donation Guideline of 2011 (Transplantation Unit MHO, 2011). But thus far, it has not observed the remarkable changes in the situation of donor donation in Malaysia and stronger policies especially organ specific policies, are urgently needed.

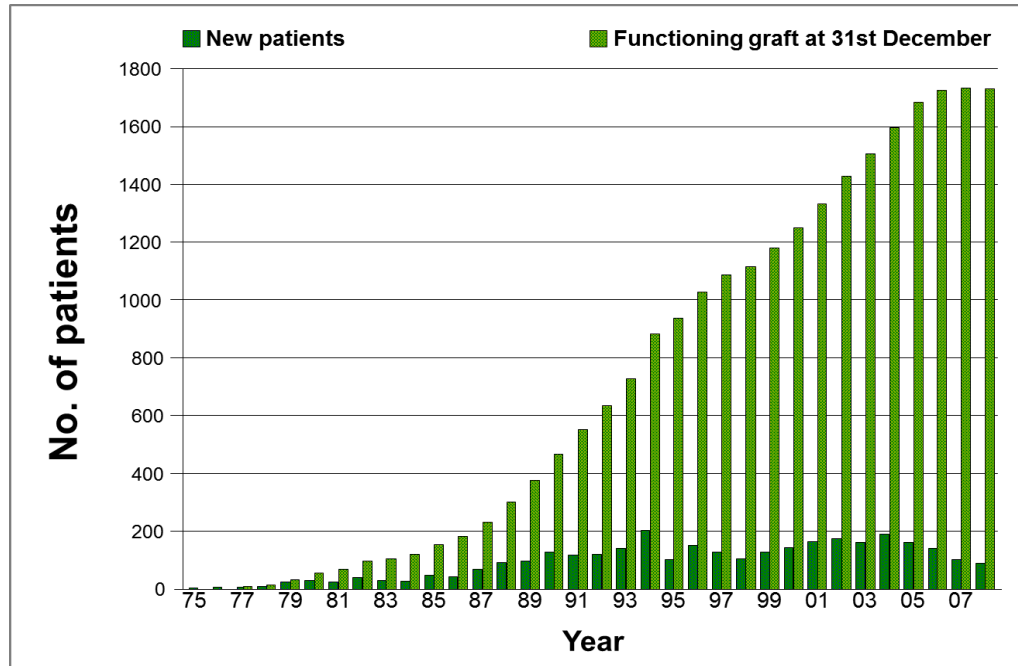
3.3 CURRENT KIDNEY DONATION SITUATION IN MALAYSIA

3.3.1 OVERVIEW

Kidney transplantation represents the highest percentage of total transplantation cases both in the world and in Malaysia. About 66,000 kidney, 21,000 liver and 6,000 heart transplantations are performed every year globally. 80% of kidneys for transplantation are sourced from living donors in this country, and some patients even resort to seeking organs from living donors in other countries (WHO, 2009; and Transplantation Unit MHO, 2011). Even though organ procurement surgery has become a standard procedure in Malaysia, as it is discussed in Chapter two, kidney donor mortality and donation policy need further improvement. In 2012, among the 15,399 patients eagerly waiting for organ transplant, 15,395 of them are kidney patients at their end-stage kidney diseases, and they are dying daily while waiting hopelessly for their organ transplants from organ donations. Steps toward kidney donor protection and fulfilled donation policy are required to improve the qualities of life of current kidney donors and to recruit potential living kidney donors to effectively resolve the current critical situations.

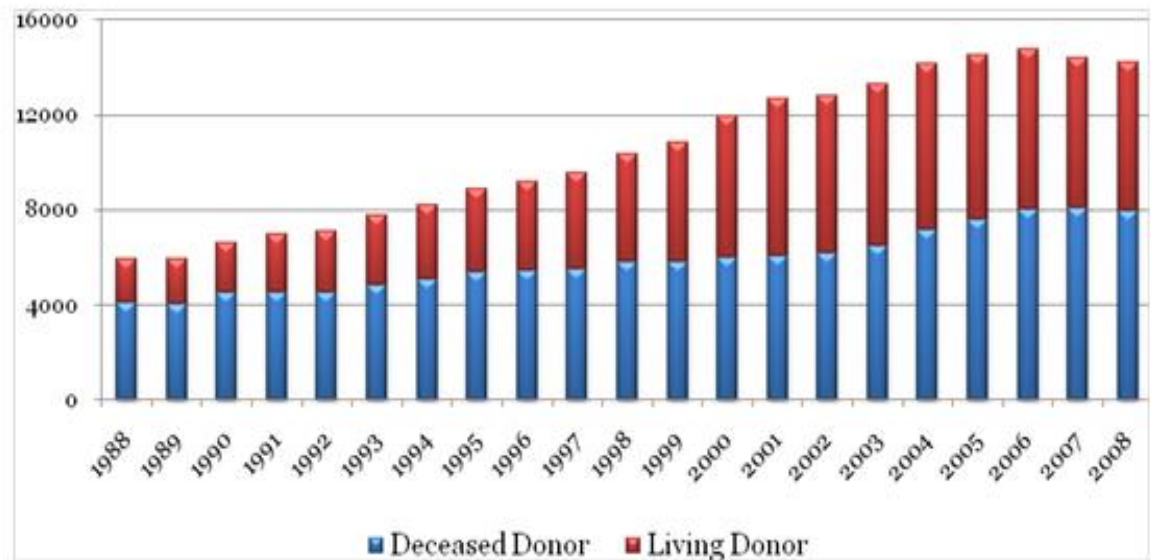
In past years, the number of kidney transplantations has been climbing to a decade's high (**Figure 3.2**). However, these numbers are currently not growing as expected mainly due to the limited availability of kidney donors in Malaysia, while, in sharp contrast, percentages of transplants from living donors have been increasing in many countries in the rest of the world. For example, more than one in three donations in the UK is now from a live donor, with a similar situation observed in smaller countries like Israel.

Figure 3.2 Stocks and Flow of Renal Transplantation in Malaysia, 1975-2008. By Zaher, ZMM et al, unpublished data



As shown in **Figure 3.3**, the number of living donors is also on the rise in the US, with most of them being kidney donors. In fact, since 2000 40~50% of donated kidneys have been from living donors in this country (Alex et al., 2010; and National Data Report). One of the reasons for the increase of US living donors is the formation of so-called "daisy chain" in addition to the impact of quality of life policy of living donors. The daisy chain involves one altruistic donor who donates a kidney to someone who has a family member willing to donate but isn't a match. The family member then donates to a recipient who is a match. The chain can be continued with several more pairs of donors/recipients and thus form a kidney donation chain under a well controlled quality of the donation administration system.

Figure 3.3 Recovered Transplant Patients in the USA



Another reason for the increased number of living kidney donor is the improved quality of modern surgery. For example, live donor nephrectomy performed by laparoscopic surgery reduces pain and accelerates recovery of the donor with a significant decrease in operative time and complications (Nicholson et al., 2011). Live donor kidney grafts have higher long-term success rates than those from deceased donors, and the application of laparoscopic nephrectomy surgery in the transplant procedures increases the living donor numbers in the US.

In comparison with the top twelve countries for organ donation and the rest of the world, Malaysia has much work to reach its goal of increasing its number of living donors. Two important measures that are urgently are the improvement of donor transplant surgery procedures and the implementation of policies to guarantee the quality of life of living kidney donors.

3.3.2 CURRENT POLICIES IN MALAYSIA

In Malaysia, related living donors are defined as parents, siblings, or close relatives who are genetically related to the recipients, or spouses and very close friends who are “emotionally related” to the recipients (Alex et al., 2010). Unrelated living donors are also legal in Malaysia. The Human Tissues Act of 1974 was the first and only related statute for a long period of time in this country, but it contained several important inadequacies (Alex et al., 2010; and National Data Reports). Firstly, the Act did not ban commercial organs. Secondly, it addressed only cadaveric organ, tissue and cell removal but did not mention living donor. Thirdly, it did not give clear definitions to crucial concepts such as “tissue”, “donor” and “recipient”. Fourthly, it did not define the “articulation of a hierarchy of relatives” which is important for a society like Malaysia with large number of relatives, and most importantly “the rights of potential live donors” which should be well protected in policies. Therefore, nationally co-ordinated policies are expected to be in place to ensure effectiveness of identifying potential donors and recipients.

As a consequence, the national transplant registry was established in 2004 to provide various information and outcome data on organ, tissue, and cell transplant recipients. In 2007, the national organ, tissue, and cell transplantation policy was formulated by various stakeholders. This policy provides governance for private and public sectors, as well as national ethical guidelines on organ transplantation. Twin principles of informed consent and altruism are fundamental in national policy, and the rights and welfare of living donors are well ensured. Thanks to these newer policies, commercial organ trade has been banned and donation related concepts have been clearly defined, which has been beneficial for

transplantation medicine since then. However, Malaysia had yet to establish a living donor registry (WHO, 2009).

As one of the milestones in Malaysian history of transplantation policies, another important policy, the Unrelated Living Organ Donation Guideline has been implemented in 2011 (Transplantation Unit MHO, 2011), in which Policies and Guidelines are published as part of the ministry's commitment to implement recommendations under the WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation of 2010. This is in line with the international community's fight against the commercialization of human parts, human or organ trafficking and transplant tourism. Under the guidelines, all organ transplants involving non-Malaysians should also be reported to the National Transplant Registry and receive prior approval from the ministry's Unrelated Transplant Approval Committee (UTAC).

Under the current available policies, the rights of organ donors have been protected, the commercialization of donated organs has been banned, and organ donations from unrelated or deceased donors have been well regulated. But thus far, living donor registry has been missing as one of the official guarantees of a truly successful living organ donation program.

3.3.3 CURRENT SITUATIONS OF KIDNEY DONATION IN MALAYSIA

Malaysia is a multi-cultural society with a population of 28.3 Million where Malays, Chinese, Indians and other ethnic groups accounted for, respectively, 60%, 23 %, and 7.1% of the total population in 2010 (Mahari, 2010). The current landscape for organ donation in

the country is of serious concern because the number of patients who need organ transplantation is increasing while the number of individuals willing to donate is significantly going down. As a multi-cultural society, the patients constitute various categories and must expect organ donors from all ethnicities to fit their needs. However, a study conducted for the purpose of identifying factors contributing to low registration of organ donors found that Malays, which form the majority of the country's population, are less willing to donate their organs compared to Chinese and Indians (**Table 3.1**).

Table 3.1 Organ & Tissue Donors Statistics.

National Transplant Resource Centre, Hospital Kuala Lumpur

Year Race	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total number of donors & Percentage
Malays	3	1	-	-	1	1	1	5	-	3	-	15 (6.36%)
Chinese	6	16	13	14	14	5	12	14	17	16	19	146 (61.86%)
Indians	3	3	14	8	1	7	11	3	6	10	9	75 (31.78%)
Total												236

Source: Organ Donation among Malaysian: The Malay Dilemma towards Social Development

According to statistics from the National Transplant Resource Centre, organ donation among the Malay majority contributed the least, only 6.36% of the total organ donation from 2000 – 2010, as compared to that of Chinese and Indians with 61.86% and 31.78% respectively (Nazni et al., 2012). The study found that two out of three factors, i.e., religion, awareness, and perception or views on organ donation, contributed to this significant

difference. It indicates that Malays are aware that organ donation is a noble practice, but religious beliefs may limit their participation. Therefore, it is recommended that a comprehensive discussion should be conducted among religious leaders so as to have an impact on changing this perception by explaining religious views on the issue of organ donation. In addition improved awareness on this topic should be promoted regularly through various media.

To evaluate organ donors' opinions of promotion factors for their donation actions, the second study attempted to seek the views of living kidney donors in Malaysia on the offering of medical benefits for their organ donation in 2011 (Makmor et al., 2011), since evidences showed that financial constraints faced by organ donors prevented them from going for post-transplant medical check-up, and up to 23% of kidney donors faced financial hardship or significant financial burden. Questionnaires were distributed to 100 organ donors, and 39 of them completed the questionnaire. Results show that 74% majority of the responders favored a sustained long-term government incentive in the form of medical benefits, and it concluded that a policy to incentivize organ donors should be adopted in the form of medical benefits by the government to meet the concern of living donors.

Another study was conducted to obtain responses from 1,233 post-secondary educated volunteers to investigate if educated Malaysians are more willing to get involved to kidney donation, and if incentives or health concerns are reasons of their unwillingness (Fong, 2011). Results show that educated people surprisingly remain unconvinced on becoming living kidney donors because 71.2% of 688 responded negatively, and the top three reasons given were all from health-related aspects but not incentives. Data indicate that the government needs to coordinate medical procedures, to awake public awareness through

public education media, and most importantly, to implement policies to protect the quality of life of living organ donors.

In the past 20 years, only a mere 2% of Malaysians have donated their kidneys, says National Kidney Foundation (NKF) founder Dr S.S. Gill (The US National Kidney Registry). He said the donation campaign programs had not been effective in raising the kidney donor rates. "If we continue with our present approach to obtain more kidney donors, we will be in the same boat in the next 20 years," he said. Current situation, research data and society responses are all calling for a quick and effective act from the government to establish immediately policies to protect the quality of life of living kidney donors, which is the only way to promote more living kidney donors and to meet the on list patients' needs.

3.3.4 UNAVAILABILITY OF LIVE DONOR REGISTRY WITH POLICIES ON QUALITY OF LIFE FOR LIVING KIDNEY DONORS

As mentioned in the earlier part of this Chapter, the live donor registry with policies on quality of life for living donor is important for the current kidney donation situation in Malaysia but is missing. Maintaining a good quality of life is helpful to the current kidney donors and to further recruit new and potential kidney donors, to remarkably improve the current very low and insufficient kidney donation situation, and to save thousands of life of those kidney patients eagerly looking forward to living instead of dying in the near future.

To fully protect the quality of living donors is an uneasy and nationwide systemic task which requires at least the following aspects: well-educated people of the awareness of the

importance of organ donation without the barriers from their traditional or religious points of view; well-developed life and medical insurance systems to insure the life and medical condition of organ donors and their families; and well-organized government set-up including registries, policies and other necessary official organizations.

For example, the organ donation environment in the US is composed of higher educated people and relatively sufficient insurance system, and most importantly well-organized government controlled organ donation and transplantation organizations. The country possesses nationwide registry system, and organ specific registry systems like the National Kidney Registry to facilitate living donor transplant specifically (Horvat et al., 2009), which defines clearly the kidney donor rights and their protections, offers a meaningful platforms for donors and recipients to share their views and to be informed of knowledge and information, and organizes of the well-known “daisy chain” of living kidney donation serial events.

The daisy chain’s formal name is Good Samaritan donation, and it encourages kidney donations between unrelated individuals and families and thus forms a donation chain. The donation chains are a major breakthrough in transplantation and are revolutionizing the process by eliminating incompatibility as a barrier to donation and providing a way for all recipients to find very well matched donors. To date the Registry has facilitated two six antigen match transplants (approximately 1% of transplants) utilizing chain matching. As the Registry pool size increases, the number of six antigen matches will increase. Many Good Samaritan donors choose to start donor chains because it is a way to help more than one person suffering from kidney failure. One chain typically facilitates 6 transplants, but in some cases it can facilitate over 20 transplants. Since the establishment of the daisy

chains by the Registry Network, the chain events have been well broadcasted by nationwide TV channels, radios, online websites and other media to educate and encourage US people to the new donation way.

It will be a long way to go for Malaysia to finally reach the living donor organization settings of the European countries and the US, but the action must be taken right now to protect the quality of life of living donor in order to enhance the world-lowest organ donation rate in the country. Since kidney is the most needed and most transplanted organ, it is here in this proposal strongly promoting the government to at least take one necessary action, to establish and implement live kidney donor registry with policies to protect the quality of life of living kidney donor in the country.

3.4 CONCLUSION

This chapter reviews how organ donation policies are set up in the world especially in the top twelve countries, and how we learned when compared to the Malaysia donation policies. It is the requirements of WHO Human Organ Transplantation Guideline for Malaysia to establish and fulfill organ donation registries and policies in our country (WHO, 2009) to fully protect the quality of life of living donors and to enhance rates of unrelated living organ donation.

European countries and the US have set up their nationwide organ donation registries and policies decades ago, while similar registries were implemented much later in Malaysia with important policies missing or inadequate. According to the EULID and the WHO guidelines, organ donor registration should include three levels: 1)The basic level, which

permits monitoring of living donation activity and percentage of donor-recipient relationship. 2)The advanced level, which collects clinical data both prior to donation and afterward to identify complications and to establish correlations. 3)The excellence level, which evaluates the quality of the entire living donation program, donor quality of life and satisfaction, as well as aspects of management, policies, and legislation (Manyalich et al., 2009).

The current organ donation registries and policies in Malaysia are in early level two – the advanced level, and additional registries and policies must be added and implemented to achieve an adequate nationwide donation system. Upon overviewing the current organ donation situation in the country, it has been seen that more than 15,000 patients are dying daily while waiting hopelessly for an organ transplant from organ donations, with most of the patients in need of a kidney while at their end-stage diseases. But realistically, only about 100 kidney transplantations are performed annually, and obviously most of patients on the waiting list will have no choices but to die while waiting for the current situation to be improved. Therefore, government action must be urgently taken to improve effectively the current nationwide organ donation situations.

Based on results from multiple studies conducted to evaluate the most important factors for living organ donations, it is found that incentives and health concerns are the two biggest concerns of current potential living donors, which should be promoted in the future policies of quality of life for living organ donors.

In summary, this chapter is strongly proposing a live donor kidney registry with policies to protect quality of life for living organ donor to be initiated and eventually implemented in

Malaysia, which is one of the two important actions to be taken of the improvement of organ donation surgery and the implementation of policies to guarantee the quality of life of living kidney donors. This is urgently needed to protect living donors' lives and to promote increasing numbers of future living donors in this country. An open, simple and easy means to use living kidney donor registry with policies to protect the quality of life of living donors could be a rapid and effective solution to the current problematic situation. It will help them to have better accesses to medical insurances, to receive financial aids from the government and local organizations, to share and receive information of organ donations, and to be organized for better performances in organ donations.

CHAPTER 4

ANALYSIS OF QUALITY OF LIFE OF LIVING KIDNEY DONORS IN MALAYSIA

4.1 INTRODUCTION

Since the implementation of the Unrelated Living Organ Donation Guideline of 2011 in Malaysia (Transplantation Unit MOH, 2011), which is the most recent released and important policy and a sign of the strong support from the Malaysian government to living organ transplantation, the kidney donation situation, which represents 99% of patients on the waiting list, remains unfortunately unchanged.

Most of current Malaysian transplanted kidneys came from deceased donors, but organ donations from living donors has remained at the same low levels in past years in the country (Horvat et al., 2009). To find a solution to the extremely low kidney donation rates in Malaysia, it is needed to understand firstly the factors that block and limit the willingness of the Malaysian people to donate their kidneys. In that regard, a questionnaire called the Short Form-36 (SF-36) Health Survey which is commonly used in the evaluation of the quality of life study of living organ donors in the world has been considered (De Groot et al., 2012). A shorter version of the SF-36, named SF-12, has also been confirmed for its specific and practical evaluation of the quality of life of living organ donor. For this purpose, a questionnaire survey is conducted among living kidney donors who have been donated their kidneys between 1990 and 2012 to investigate their quality of life post-donations.

4.2 ANALYSIS OF QUALITY OF LIFE OF LIVING KIDNEY DONORS

In this survey, 80 respondents out of 170 living kidney donors have responded to the appointments and completed the survey. The Questionnaire Survey for the living kidney donors is divided into two main sections: Section A – Backgrounds of Respondents; Section B – Quality of Life of Respondents; Section C – Statement of Donation; and Section D – Support after Donation. The study of quality of life of kidney donors longitudinally and cross-sectionally will be beneficial for the determination and identification of current kidney donors' health situation and living condition in the country. The results of Background have been separated from the results of Quality of Life which have been analyzed as follows.

4.2.1 DESCRIPTIVE STATISTICS

This questionnaire survey is a follow-up assessment with each subject being evaluated before and after kidney donations. Section A contains general questions to investigate the backgrounds of the living donors.

4.2.1.1 Descriptive Statistics of Backgrounds

This section provides a detailed descriptive statistics for all questions in Section A – Background, and data were presented as frequencies and percentages as appropriate. The Demographic Analysis of the Section A data (Table 4.1) summarized the results of the responses from the 80 living kidney donors. A total of eight questions were asked which included age, gender, ethnic, marital status, education, income, employment and relationship with recipient. In addition, conditions before and after their kidney donations were also compared.

With regard to age before donations, more than 70 percent of donors were between 30 to 60 years old. The percentages of 31 – 40 years old, 41 – 50 years old, and 51 – 60 years old were, respectively, 25, 35, and 16.3 percent. In addition, percentages of donors who were 21 – 30 years, younger than 20, and older than 60 years old were, respectively, 11.3, 2.5 and 3.7 percent. When the survey was conducted (after donations), more than 70 percent of donors were between 40 to 70 years old in which they were 41 – 50 years old (28.7 percent); 51 – 60 years old (22.5 percent); and 61 – 70 years old (22.5 percent), respectively. Besides these, 31 – 40 years old were 12.5 percent, and younger than 30 or older than 70 years old were the least of 6.3 and 7.5 percent respectively. The mean age before donations was 44.24 ± 11.77 years, and the mean age after donation was 51.83 ± 12.62 years

Regarding the genders of the 80 living kidney donors, most of them were females with 63.7 percent (51 cases), and only 36.3 percent (29 cases) males. This is similar to reports from other countries where similar surveys were conducted and indicates

that the data are within the normal ranges of sexes (Mjoen et al., 2011; and Clemenns et al., 2011).

The third question on the Questionnaire was marital status. Results show that the majority of the donor respondents was married and represented 80 percent (64 cases) of the total respondents. Respondents that were single represented 16.3 percent (13 cases), and widow or divorced respondents were only 3.8 percent (3 cases).

The fourth question designed was educational status of the donors. More than half of donors had received secondary education and represented 57.5 percent (46 cases) of the respondents. The majority of the remainder received primary education and represented 32.5 percent (26 cases), and the least are those who received tertiary education or others as 7.5 (6 cases) and 2.5 (2 cases) percent respectively. This question is included because studies in the US and Europe showed that education attainment could be a strong predictor of positive attitude towards organ donations (Makmor et al., 2010).

The personal incomes before and after donations was also surveyed. Results showed that before donations, 45.1 percent (35 cases) had no incomes; 30 percent (24 cases) had medium incomes of RM1,000 ~ 2,000, 10 percent (8 cases) had incomes lower than RM1,000, 8.8 percent (7 cases) had incomes of RM2,001 ~ 3,000, and 6.3 percent had incomes of RM3,001 ~ 4,000. Currently after donations, those donors with no incomes were reduced to 32.3 percent (25 cases), those with medium incomes of RM1,000 ~ 2,000 reduced to 26.3 percent (21 cases), those

with incomes lower than RM1,000 increased to 15 percent (12 cases), those with incomes of RM2,001 ~ 3,000 increased to 12.5 percent (10 cases), those with incomes of RM3,001 ~ 4,000 increased to 11.3 percent (9 cases), and those with highest incomes of higher than RM4,001 only presented after donations which is 3.8 percent (3 cases).

The total employment rate of those responding donors before donations was 54.8 percent (44 cases), in which 17.5 percent (14 cases) was self-employed, 11.3 percent (9 cases) was public sector employees, 18.8 percent (15 cases) was private sector employees, and 7.5 percent (6 cases) was other employees. After donations, the employment rate increased to 67.5 percent (54 cases), in which 20 percent (16 cases) was self-employed, 15 percent (12 cases) was public sector employees, 23.8 percent (19 cases) was private sector employees, and 8.8 percent (7 cases) was other employees.

The majority of the responding kidney donors had first degree relationships with their recipients with 75 percent (60 cases), and were emotional related to their recipients with 21.3 percent (17 cases). Only a few donors had first degree or other relationships with their recipients which were 2.5 (2 cases) and 1.3 (1 case) percent respectively.

Table 4.1 Demographic Analysis for the Study (n=80)

Demographic Variables	Frequency	Percentage (%)
Gender		
Male	29	36.3
Female	51	63.8

Ethnic

Malay	16	20
Chinese	50	62.5
Indian	14	17.5

Marital Status

Single	13	16.3
Married	64	80
Widow/Divorced	3	3.8

Highest Education

Primary School	26	32.5
Secondary School	46	57.5
Tertiary	6	7.5
Others	2	2.5

Monthly Income (Current)

None	25	32.3
Less than RM1000	12	15
RM1000-RM2000	21	26.3
RM2001-RM3000	10	12.5
RM3001-RM4000	9	11.3
RM4001 and above	3	3.8

Monthly Income (At the Time of Donation)

None	35	45.1
Less than RM1000	8	10
RM1000-RM2000	24	30
RM2001-RM3000	7	8.8
RM3001-RM4000	5	6.3

Relationship with Organ Recipient

First Degree Relative	60	75
Second Degree Relative	2	2.5
Emotionally Related	17	21.3
Others	1	1.3

Age (Current)

21 – 30	5	6.3
31 – 40	10	12.5
41 – 50	23	28.7
51 – 60	18	22.5
61 – 70	18	22.5
71 and above	6	7.5

Age (At the Time of Donation)		
Below 20	2	2.5
21 – 30	9	11.3
31 – 40	20	25
41 – 50	28	35
51 – 60	13	16.3
61-70	8	3.7

4.2.1.2 Cross-tabulation Analysis – The Relationship between the Living Kidney Donors and Their Organ Recipients

Crosstabs analysis was used to analyze the relationships between the living kidney donors and their organ recipients of different ethnicity (**Table 4.2**). Data showed that among all of the relationships like 1st relative, 2nd relative, emotional related and others, Chinese ethnicity is predominant in living kidney donations. In contrast, Malay ethnicity has donation rates that are similar to Indian ethnicity, even though Malay represents the majority in our country. Our results are similar to a previous report of total organ donations among different ethnicities which included living and deceased organs (Nazni et al., 2012).

Table 4.2 Ethnic Towards the Relationship with their Organ Recipients

Ethnic (%)	1st Degree Relative	2nd Degree Relative	Emotionally Related	Others	Total (N)
Malay	13.75	1.25	5	0	16
Chinese	47.5	1.25	12.5	1.2	50
Indian	13.75	0	3.8	0	14
Total	75	2.5	21.3	1.2	100/80

4.2.1.3 Descriptive Statistics of Quality of Life

Section B and C Survey contains some important questionnaires which are the central part of this research. It includes our aims related to the quality of life of living kidney donors in terms of psychosocial and physical health. Among the respondents, more donated their organs between the year of 2005~2009 with 41.3 percent (33 cases) (**Table 4.3**), and others spread evenly into 1995~1999, 2000~2004, and 2010~2012 with 20 percent (16 cases), 20 percent (16 cases), and 23.7 percent (19 cases), respectively. Fewer individuals donated between 1990~1994 with 7.5 percent (6 cases).

An important indicator of physical health condition is level of activity. The majority (92.6 percent) of living kidney donor respondents did not have or had limited activity during a typical day of their post-donation life with 48.8 percent (39 cases) and 43.8 percent (35 cases) respectively (**Table 4.3**). Only 7.5 percent (6 cases) had major limits of their daily activity. When they were asked if they had “less than they would like” physical health condition after donations, the answer was “rarely” (mean \pm SD = 3.88 ± 1.02 ; SD means standard deviation), which indicated that the majority did not have any limit or incapability of their physical conditions.

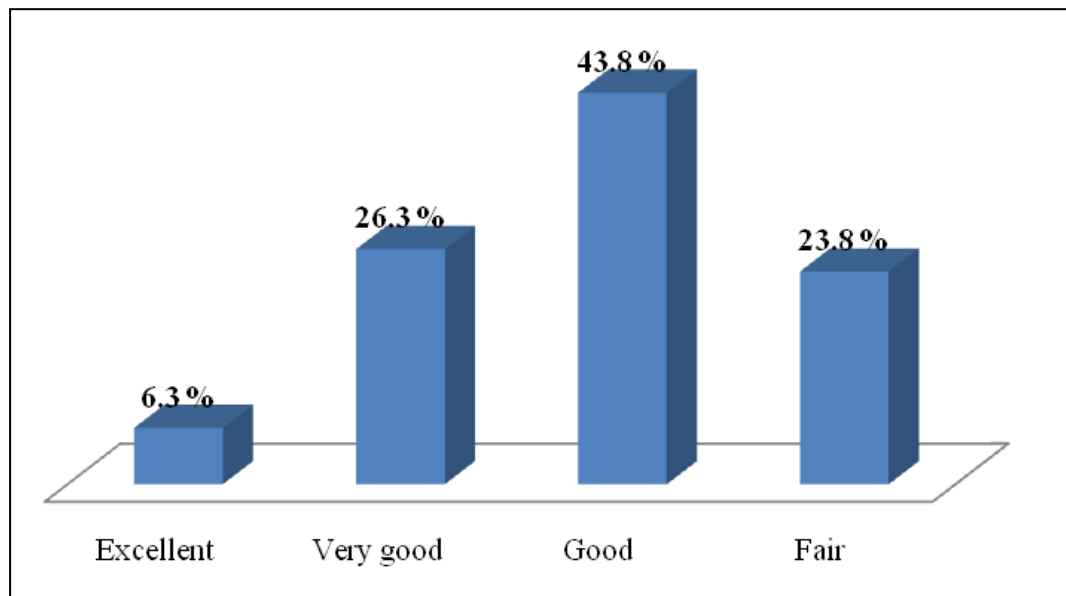
Another indicator of physical health condition is pain interfering with normal work. The majority (75.1 percent) of donor respondents had no or had some pain interfering with their normal work, with 33.8 percent (27 cases) and 41.3 percent (33 cases), respectively. Some respondents had moderate pain interfering with normal work with 21.3 percent (17 cases), and only a few had more pain interfering with normal work with 3.8 percent (3 cases) (**Table 4.3**).

Table 4.3 Year of Donation, Limitation and Work Interfering

Variables	Frequency	Percentage (%)
Year of Donation		
1990 – 1994	6	7.5
1995 – 1999	16	20
2000 – 2004	16	20
2005 – 2009	33	41.3
2010 – 2012	19	23.7
Limitation of Activities During Typical Day		
Yes, Limited A Lot	6	7.5
Yes, Limited A Little	35	43.8
No, Not Limited At All	39	48.8
Pain Interfere with Normal Work		
Not At All	27	33.8
A Little Bit	33	41.3
Moderately	17	21.3
Quite A Bit	3	3.8

As a result, more than 76 percent of donor respondents had good, very good or excellent health after donations with 43.8 percent (35 cases), 26.3 percent (21 cases), and 6.3 percent (5 cases) respectively. Only 23.8 percent (19 cases) had fair health conditions indicating that the majority of the kidney donors are living a healthy life post organ donations (**Figure 4.1**).

Figure 4.1 Current Health of Living Kidney Donors (n=80)



With regard to psychosocial health conditions, most of the donor respondents felt calm and peaceful all of the time (21.3 percent), or most of the time (36.3 percent). However, 26.3 percent felt peaceful some of the time, 12.5 percent felt it only a little of time, and 3.8 percent never felt it (**Table 4.4**). Another emotional indicator is energy level, where 42.5 percent of donors had a lot of energy most of the time after donations, 7.5 percent had energy all of the time, 28.8 percent had energy some of the time, 17.5 percent had energy only a little of the time, and 3.8 percent of them never had energy. When they were asked if they had “less than they would like” and limited emotional health conditions after donations, the answers went to “rarely” (mean \pm SD = 3.78 ± 0.98), which indicated that the majority did not have any limit or problem of their emotional conditions.

The final emotional indicator we measured was depression, where 40 percent of the donor respondents never felt down and depressed, 31.3 percent of them felt a little

of down and depressed, 25 percent felt down and depressed sometimes; 2.5 percent of them felt down and depressed most of the time; and 1.3 percent of them felt it all of the time (**Table 4.4**). When the respondents were asked how much of the time had their physical health or emotional problems interfered with their social activities, half of them (53.8 percent) said it never happened, 18.8 percent said it happened only rarely, 26.3 percent of them said it happened sometimes, and 1.3 percent said it happened most of the time. None of them said it happened all of the time. Answers went to “rarely” (mean \pm SD = 4.25 \pm 0.89), which indicated that the majority did not have physical health or emotional problems interfering with their social activities.

Table 4.4 Emotional Situations

Statement (%)	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Have you felt calm and peaceful?	21.3	36.3	26.3	12.5	3.8
Did you have a lot of energy?	7.5	42.5	28.8	17.5	3.8
Have you felt downhearted and depressed?	1.3	2.5	25	31.3	40
How much of the time has your physical health or emotional problems - interfered with your social activities?		1.3	26.3	18.8	53.8

When the donor respondents were asked about their willingness to donate again, 67 percent of them indicated that they would donate their kidney again, and 97.5 percent did not regret their decisions of donation (**Table 4.5**). 93.8 percent agreed that donations have made their lives more meaningful, 92.5 percent said the donations have made them respected by their families, and 93.8 percent said the donations improved their relationships with their recipients. 96.3% percent said they would strongly encourage other people to donate their organs.

Table 4.5 Statement and Decision for Donation

Statement	Yes		No	
	f	%	f	%
If it were possible, I would donate my kidney again	54	67.5	26	32.5
I would strongly encourage others to donate their organ	77	96.3	3	3.8
I regretted my decision to donate my organ	2	2.5	78	97.5
Donation makes my life more meaningful	75	93.8	5	6.3
Donation improved my relationship with the recipient	75	93.8	5	6.3
Donation makes me respected in the family	74	92.5	6	7.5

4.2.1.4 Descriptive Statistic of the Support after Donation

For Section D, the questionnaire is on the support after donation, 80 percent of the donor respondents thought that the government should set-up clinics for donors, and 88.8 percent thought that all donors should be systematically registered and monitored as of living donor registry. Only 3.8 percent of each of the categories did not respond, and 16.3 and 7.5 percent were undecided, respectively (**Table 4.6**). When the question of whether to be considered or treated as a patient was asked, 67.5 percent of them disagreed, only 18.8 percent agreed, and 13.8 percent remained undecided.

Table 4.6 Government Policies

Statement	Yes		No		Undecided	
	f	%	f	%	f	%
I should be considered/treated as a patient too	15	18.8	54	67.5	11	13.8
The government should set-up clinics for donors	64	80	3	3.8	13	16.3
All donors should be systematically registered and monitored (living donors registry)	71	88.8	3	3.8	6	7.5

4.2.2 INFERENCE STATISTICS AND DISCUSSION

The inferential statistic data have been analyzed using SPSS 12.0 of *Paired T-Test* to reveal the relationships between different domains (health, income, employment and donation), and the *Independent Sample T-Test* to reveal the relationships between gender and health problem, before and after kidney donations.

4.2.2.1 ASSOCIATION ANALYSIS – SIGNIFICANT RELATIONSHIPS

4.2.2.1.1 Examination of Hypothesis One – Health between Donors & Recipients

The purpose of hypothesis one is to determine whether there is a significant relationship between the current health conditions of kidney donors towards the current health conditions of kidney recipients. The hypotheses build for these variables are:

H_{01} : *There is no significant relationship between the current health conditions of kidney donors towards the current health conditions of kidney recipients.*

H_1 : *There is a significant relationship between the current health conditions of kidney donors towards the current health conditions of kidney recipients.*

Table 4.7 shows the correlation between the current health conditions of the living kidney donors and the current health conditions of the kidney recipients. The bivariate correlation test was applied in order to determine the association of each independent variable with the dependent variable. The output indicates that there are significant positive relationships between these two variables where $r = 0.30$, $p < .01$. Therefore, H_{01} hypothesis is rejected. This result shows that the healthier the living kidney donors were, the healthier the kidney recipients would be. There was strong relationship between the independent variable (current health of kidney donors) and the dependent variable (current health of kidney recipients).

The result is significant since the results of donor health above indicate positive responds from the living donors where most of the donors responded positively on their physical and emotional health conditions. When the donors responded with positive thoughts about their conditions, it reflected directly that their body and organ functions were perfectly well. And when the recipients responded positively, it meant the donated healthy organs cured their diseases and improved their health conditions. Consequently, the positive responses of their health from the donors are associated closely with positive responses from the recipients, which indicating successful organ donations and transplantations.

Table 4.7 Relationship Analysis between the Current Health of Living Kidney Donors towards the Current Health of Kidney Recipients

Variable	Pearson Correlation	Sig. (2-tailed)	Decision
Current Health of Kidney Recipients	0.30 **	0.00	H_{01} rejected

** Correlation is significant at 0.01 level (2-tailed)

4.2.2.2 COMPARISON ANALYSIS – SIGNIFICANT DIFFERENCES

4.2.2.2.1 Examination of Hypothesis Two – Previous and Current Income (Paired Sample T-Test)

The purpose of the hypothesis two is to find that if there is a significant difference between the monthly incomes before donations and the monthly incomes after donations of the living kidney donors. The hypotheses build for these variables are:

H_{02} : *There is no significant difference between the monthly incomes before donations and after donations of the living kidney donors.*

H_2 : *There is a significant difference between the monthly incomes before donations and after donations of the living kidney donors.*

The paired sample statistical analyses on **Table 4.8** shows the mean of the monthly incomes before donations as 2.18, and the monthly income after donations as 2.66. The standard deviations for monthly incomes before and after donations are 1.32 and 1.53. The output indicates that significant positive relationships exist between these two variables where $t(79) = 4.77$, $p < 0.05$. Therefore, H_{02} hypothesis is

rejected. This result shows that the monthly incomes were significantly higher after donations when compared to the incomes after donations. There were strong relationship between the independent variable (incomes before donations) and the dependent variable (incomes after donations).

The bivariate correlation was undertaken between the income rates before and after donations towards the achieving of the kidney transfers. It was hypothesized in H_2 that a significant relationship exists between these two variables. Results of the correlation indicate that the monthly income changes before and after donations are associated strongly with the activities of kidney donations. It shows that the living kidney donations did not hurt the capabilities of the donor of job finishing and money earning, which meant that living donors maintained their working and living conditions and abilities.

Table 4.8 Comparison Analysis between Current Income and Income at the Time of Donation of Kidney Donors

Variable	Mean	Std. Deviation
Current Income	2.66	1.53
Income at the Time of Donation	2.18	1.32

	<i>t</i>	<i>df</i>	Sig. (2-tailed)	Decision
Paired (Current Income and Income at the Time of Donation)	4.77	79	0.00	H_{02} rejected

4.2.2.2.2 Examination of Hypothesis Three – Employment Status before and after Donations (Paired Sample T-Test)

The third hypothesis intends to find that if there is a significant difference between the employment status before and after the donations of the living kidney donors. The hypotheses constructed for these variables are:

H_{03} : *There is no significant difference between the employment status before and after donations of the living kidney donors.*

H_3 : *There is a significant difference between the employment status before and after donations of the living kidney donors.*

The analyzed results show that the mean of employment status is as 3.03 ± 1.88 (mean \pm SD) before donations, and as 3.45 ± 1.81 after donations (**Table 4.9**). There is positive correlation between the two variables because $t(79) = 2.91$, and $p = 0.05$ indicating that the higher employment status of the donors after donations

are associated with the lower employment status before donations toward the actions of kidney donation. This means that the H_{03} is rejected.

As in H_3 , it was hypothesized that significant relationship exists between these two variables. Results of correlation indicate that the higher employment rate after donations is associated with lower employment rate before donations towards the achieving of the kidney transfer. This result shows that the individual working and socialization abilities of the living organ donors were positive, and did not decrease post the single kidney losses. The positive results support the understanding and opinion that the kidney donations among living donors will not affect their living condition and lives, and it is higher possible that kidney donors are able to live their normal lives and maintain their living conditions.

Table 4.9 Comparison Analysis between Current Employment Status and Employment Status at the Time of Donation

Variable	Mean	Std. Deviation
Current Employment Status	3.45	1.81
Employment Status at the Time of Donation	3.03	1.88

	<i>t</i>	<i>df</i>	Sig. (2-tailed)	Decision
Paired				
(Current Employment Status and Employment Status at the Time of Donation)	2.91	79	0.05	H_{03} rejected

4.2.2.2.3 Examination of Hypothesis Four – Genders and Physical Health Problems (Independent Sample T-Test)

The fourth hypothesis of the study is to determine if there is a significant difference between genders (female and male donors) and the physical health problems of regular daily activities from kidney donors. The related hypotheses are:

H₀₄: There is no significant difference between genders and physical health problems of regular daily activities from kidney donors.

H₄: There is a significant difference between genders and physical health problems of regular daily activities from kidney donors.

The output of **Table 4.10** shows the result of mean \pm SD for male is 3.81 ± 1.09 and for female is 3.75 ± 0.92 . The Levene's Test for Equality of Variances shows $p > 0.05$ which implies that equal variances is assumed. The analysis shows that there is no significant relationship between the male and female donors where $t = 1.03$, $df = 62.84$ and $p = 0.30$. This shows that H_4 is rejected which indicating that genders have no impact on the physical health problems of daily activities from living donors.

Table 4.10 Comparison Analysis between Gender towards the Kidney Donors' Physical Health Problem for Regular Daily Activities

			Variable	Mean	Std. Deviation
			Male	3.81	1.09
			Female	3.75	0.92

			<i>t</i>	<i>df</i>	Sig. (2-tailed)	Decision
Gender	towards	Physical	0.23	50.53	0.82	H_4 rejected
Health Problem						

4.2.2.2.4 Examination of Hypothesis Five – Gender towards Emotional Problem (Independent Sample T-Test)

The fifth hypothesis of the study is to determine if there is a significant difference between genders and emotional problems of regular daily activities from kidney donors. The related hypotheses are:

H_{05} : *There is no significant difference between genders and emotional problems of regular daily activities from kidney donors.*

H_5 : *There is a significant difference between genders and emotional problems of regular daily activities from kidney donors.*

The output at **Table 4.11** below shows the result of mean \pm SD for male is 4.03 ± 0.96 and for female is 3.79 ± 1.05 . The Levene's Test of Equality of Variance shows that the p value is bigger than 0.05, which implies that the equal variances are assumed. The analysis shows that there is no significant relationship between the male and female donors where, $t = 0.23$, $df = 50.53$ and $p = 0.82$. This shows

that H_5 is rejected which indicating that genders have no impact on the emotional health problems of daily activities from living donors.

Table 4.11 Comparison Analysis between Gender towards the Kidney Donors' Emotional Problem for Regular Daily Activities

Variable	Mean	Std. Deviation
Male	4.03	0.96
Female	3.79	1.05

	<i>t</i>	<i>df</i>	Sig. (2-tailed)	Decision
Gender towards Emotional Problem	1.03	62.84	0.30	H_5 rejected

4.2.2.2.5 Differences on Ethnicity towards Kidney Donors Physical or Emotional Problems Interfering with Social Activities (One-way ANOVA)

A one-way ANOVA test was performed to analyze if the kidney donors' physical and emotional problems have been interfering with their social activities among different ethnic groups as Malay, Chinese and Indian. Analyzed results of Table 4.12 show that $F(2, 77) = 3.55$, $p = 0.03$ ($p < 0.05$) indicating that there are significant differences between ethnic groups of their physical or emotional problems interfering with their social activities. The analyzed data mean that different ethnic groups of living donors will be affected by their ethnic related physical and emotional problems which will modify their social activities probably due to different education, culture and religion backgrounds. These results also imply that the enhancements and set-up of government policies and donor specific

registry systems may help living donors to well control their social activities after organ donations.

Table 4.12 ANOVA Summary Table: Ethnic and Physical or Emotional Problem Effects Social Activities

Aspect / Variable	<i>df</i>	F	Sig.
Ethnic	2, 77	3.55	0.03

4.3 COMPARING WITH OTHER QUALITY OF LIFE STUDIES IN MALAYSIA

To the knowledge, a study of quality of life of living kidney donors has not been conducted in any scale in Malaysia, although a few reports similar to this survey have been published as partial or uncompleted studies in the past years. Two of the reports are about living donor education in regular populations (Makmor et al., 2010; and Nazni et al., 2012), and only one report is related to the quality of life of living organ donor which shows that the majority of respondents favored a long-term incentive policy in the form of medical benefits (Makmor and Kun et al., 2011). More studies of quality of life are urgently needed and must be conducted to show the current situations of living donor's life in the country, in order to encourage organ donations in the population countrywide and offer references and information to the establishments of related policies.

4.4 COMPARING THE ANALYSIS WITH SIMILAR STUDIES OF OTHER COUNTRIES

Studying quality of life from living organ donors is relatively new. Similar studies conducted in Asian countries were on the same levels and scales as what have reported in this chapter, and drawing similar conclusions. For example, a report from India shows a significant improvement in quality of life among three of the four domains comparing before and after kidney donations. Similar to the study, females constituted 73% of the population; and education status and marital status did not make any difference in quality of life. The authors concluded that living related kidney donations improves the quality of life of donors (Vemuru et al., 2011).

But studies reported from Europe and the US are more advanced and trying to explore deeper into different levels and understandings of quality of life. One of the typical reports from Norway shows that Norwegian kidney donors are mostly first-degree relatives, and they are fully reimbursed and offered life-long follow-up. All inhabitants are provided universal healthcare. The study contacted 1984 cases of kidney donors through the Norwegian Renal Registry and found the following facts: Risk factors for having doubts were graft loss in the recipient, medical problems after donations, unrelated donor; older age at donation was associated with lower risk; the majority of them preferred to donate again (Mjoen et al., 2011), which is similar to the finding.

A multi centers report from Canada, Australia and Scotland shows that donors who donate a kidney in centers that use routine pre-transplant donor evaluation have good long-term quality of life compared to healthy non-donor controls (Clemens et al., 2011). There were

no differences between donors to recipients who had an adverse outcome (death, graft failure) and those donors where the recipient did well, which is different from the report where the good health condition of donors is closely related to the good condition of their recipients.

Another study from Australia going into the depth of emotional health found that kidney donation has a profound and multifaceted impact on the lives of donors and requires them to re-negotiate their identity, roles, and relationships. Strategies are needed to help the donors to have balanced expectations and relationships with the recipient and the family (Tong et al., 2012). A report from Germany found that the impact on physical quality of life seems to persist for at least three months after kidney donations, and it could be demonstrated that in the context of living donations, comparison with healthy individuals provide more adequate reference data than comparison with regular populations (including healthy and non-healthy people) (Kroencke et al., 2012). Finally, a report from Taiwan found that living organ donation is a treatment option that requires acceptance by both the donor and the family, which is an enormously stressful process, and living donors need adjustment strategies to maintain their peace of mind throughout the process (Weng et al., 2012).

When comparing the study to these international reports, many similarities and agreements can be found. But in most of the cases, it appears that it is needed to do more studies and explore deeper into the complex aspects of donation decision making, donor and family relationship, donor and recipient relationship, donor emotional and physical changes pre and post donations, etc. These explorations of quality of life of living donors require a fully set up donor registry system and full support by government policies.

4.5 CONCLUSION

To analyze the quality of life of living kidney donors in the country, a shorter version of the Short Form 36 (SF-36), the SF-12 of health survey was conducted in 80 respondents out of 170 contacted living kidney donors of the donation time periods of 1990 to 2012. The overall results are that the response rate was 47.0 percent and the mean age was 44.24 ± 11.77 years. Females constituted 63.8 percent of the donors. The study showed improvements in the qualities of lives among most of the related domains.

Descriptive analysis was used to analyze the backgrounds of the living kidney donors. It is found that the majority of them was married and represented 80 percent of the donors. When the education levels, personal incomes and employment rates before and after the organ donations were compared, it is found that both the personal incomes and employment rates did not decrease after the kidney donations. With regarding the relationships of the living donors, the majority of them belonged to first degree relationships to their recipients and represented 75 percent. When Crosstabs Analysis was used to analyze the relationships between the living kidney donors and their organ recipients of different ethnics, Chinese ethnic is found predominant among living kidney donors, but not Malay ethnic which donation rates are similar to the Indian ethnic, even though Malay is the major population in the country.

Descriptive analysis was also used to analyze the qualities of lives of the living donors, which include time periods, physical and psychosocial health conditions. It is found that the peak of donation period was the years of 2005~2009 which was 41.3 percent; and the

donations of the years of 1995~1999, 2000~2004, and 2010~2012 were similar representing around 20 percent; and the years of 1990~1994 were the lowest period representing only 7.5 percent of the total kidney donations between 1990 and 2012.

For physical health conditions, activity limitation as one of the important signs shows that the majority (92.6 percent) of the donor respondents did not have major limit or incapability of their physical conditions; and pain interfere of normal work as another sign shows that the majority (75.1 percent) did not have or have a little bit pain-related interferes of their normal works. As the consequences, more than 76 percent of donor respondents had good, very good or excellent health after donations which indicating that the majority of the kidney donors are living their healthy lives post organ donations.

With regarding psychosocial health conditions, emotional situation is one of the important factors in which the majority (56.6 percent) of the donor respondents felt calm and peaceful in their life; and energy as another emotional factor, 50 percent of them had energy at most or all of the time; and the majority did not have major limit or problem of their emotional health conditions. The final emotional situation measured was depression, in which 40 percent of the donor respondents never felt downhearted and depressed; 31.3 percent of them felt a little of downhearted and depressed; but the majority did not have physical health or emotional problems interfering with their social activities.

When the donor respondents were asked about their willing of re-donation, 67 percent of them would donate their kidneys again; and 97.5 percent did not regret their decisions of donation; 93.8 percent agreed that the donations have made their lives more meaningful, 92.5 percent said the donations have made them respected in their families, and 93.8

percent said the donations improved their relationships with their recipients. 96.3% percent said they would strongly encourage other people to donate their organs.

For those questionnaires about government policies, 80 percent of the donor respondents thought that the government should set up clinics for donors, 88.8 percent thought that all donors should be systematically registered and monitored as of living donor registry, and 67.5 percent disagreed to being considered or treated as patients.

Inferential analysis was used to analyze significant relationships and differences among different survey domains. The Association Analysis for significant relationships shows that the healthier the living kidney donors were, the healthier the kidney recipients would be which indicating that healthy organ donations are one of the important factors for successful kidney transplantations.

The comparison analysis for significant differences shows that the monthly incomes and employment rates were significantly higher after donations when compared to the incomes before donations which show that the living kidney donations did not hurt their working and socialization abilities, and it is highly possible that kidney donors are able to live their normal lives and maintain their living conditions. Another comparison analysis shows that genders have no impact on the emotional health problems of daily activities from living donors. But different ethnic groups of living donors will be affected by their ethnic related physical and emotional problems which will modify their social activities probably due to different education, culture and religion backgrounds.

As summary, the analyzed data show the following three major conclusions: firstly, the qualities of lives of living kidney donors have been improved after organ donations; secondly, the living capabilities of the living kidney donors did not decrease but were maintained indicating that living donation should be encouraged and promoted among the Malaysian populations, and these data can be used to educate people in the country to have better confidences and stronger potencies to organ donation; thirdly, the results suggest that the enhancements and set-up of government policies and donor specific registry systems are necessary for helping living donors to receive supports from the society, and well control their social activities after organ donations which will promote donor educations and improve donation awareness among regular populations. As the knowledge, there is no currently full scale of analysis reported of donor quality of life as have done in Malaysia, and more analyses with bigger scales and deeper explorations must be conducted to improve the living donation situations. To reach this goal, governmental policies and living kidney donor registry system must be set up in Malaysia to fully support further studies and living donors' lives.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 LITERATURE REVIEW - THE QUALITY OF LIFE OF LIVING DONORS

To establish a system of living donor registry, especially living kidney donor registry since 99 percent of the patients on the organ waiting list is kidney patients, is recommended by the WHO to the Malaysian organ transplantation. This is urgently needed to improve the current organ donation situation to rescue more than 15,000 patients with end-staged organ diseases on waiting list for available organs in the country. Living organ donation is depending on people's awareness and decision making, and thus can be enhanced by the efforts and governmental policies. Living organ donors, including kidney donors, are on a rise in the world in the past years, but are decreasing in Malaysia indicating that there is a higher potency in enhancing the organ donation numbers in the near future.

5.1.1 THE DONOR QUALITY OF LIFE IN MALAYSIA

The Chapter One and Chapter Two give the backgrounds, purposes and methods of the study, and summarize the countrywide situations of the quality of life of living donor in Malaysia, which shows that among the five major organ donation models in the world like Commodification, Conscription, Presumed Consent, Required Response, and Compensation, only the last two – Required Response, Compensation are applicable in the country due to culture and moral conscience reasons, and thus the organ donor sources are limited. It also concludes that organ donation imposes low health risk and possesses high

survival and morbidity rates. The donor mortality for kidney donation in Malaysia is 3.1 deaths in 10,000 donations which are around 99.7 percent even though the medical practitioners are working towards the achievement of 100 percent successful rate like other countries.

Among the factors affecting the physical health of living kidney donors, three of them are the ones with most occurrences like the physical functioning, physical limitation and bodily pain. In addition, those factors affecting the emotional health of living donors include relationships between donors and recipients as well as family members, and anxieties and depressions could come from financial burdens coupled with physical deteriorations. As solutions to these physical and emotional health problems, the accesses to health care system, life insurance system, and reimbursement policy may give supports to living donors. On the other hand, excellent post-operative cares and follow-up visits may help to improve quality of life even in the situation that the insurance and reimbursement policies are unavailable.

5.1.2 THE DONOR QUALITY OF LIFE INTERNATIONALLY

Chapter 2 reviews the quality of life of living organ donors in other countries around the world. For instance, lots of countries like Norway, Canada, Scotland, and Australia offer universal health care systems, full reimbursement policies and good life insurances; and prove that the accessibilities of donors to the health care systems, insurance policies and financial reimbursements play their important roles in maintaining, if not improving, donor's quality of life. As consequences, living donors of these countries show positive and comparable improvements in all eight aspects of the quality of life. As additional example, living donors in India have great post-transplant cares. All of the Indian organ donors receive early rehabilitations, attend follow-up regularly (4, 6, 8 and 12 months), and are able to return to work within 4 weeks, which indicating that higher qualities of post-transplant cares can contribute to donor's quality of life remarkably.

5.2 CURRENT POLICIES OF ORGAN DONATIONS IN MALAYSIA

Chapter Three reviews organ donation policies set up in the world especially in the twelve countries with top donation rates in the world, and what is learned when compared to the Malaysia donation policies. It is the requirements of WHO Human Organ Transplantation Guideline for Malaysia to establish and fulfill organ donation registries and policies to fully protect the quality of life of living donors and to enhance the rates of related and unrelated living organ donations. European countries and the US have set up their nationwide organ donation registries and policies decades ago, while similar registries were implemented much later in Malaysia with important policies missing or inadequate.

The current organ donation registries and policies in Malaysia are in early level, and additional registries and policies must be added and implemented to achieve an adequate nationwide donation system. Upon overviewing the current organ donation situation in the country, what is seen is that more than 15,000 patients are dying daily while waiting hopelessly for an organ transplant comparing to only about 100 kidney transplantations performed annually. Therefore, government action must be urgently taken to improve effectively the current world-lowest organ donation situations.

Based on results from multiple studies conducted to evaluate the most important factors for living organ donations, it is found that incentives and health concerns are the two biggest concerns of current potential living donors, which should be promoted in the future policies of quality of life for living organ donors.

5.3 DISCUSSION OF THE QUALITY OF LIFE OF LIVING KIDNEY DONORS

Chapter Four analyzes the quality of life of living kidney donors in the country in order to offer effective solutions to the current donation situations. It is done by using a shorter version of the Short Form 36 (SF-36), i.e., the SF-12 of health survey, which was conducted in 80 respondents out of 170 contacted living kidney donors of the donation time periods of 1990 to 2012. The overall results are that the response rate was 47.0 percent and the mean age was 44.24 ± 11.77 years. Females constituted 63.8 percent of the donors. the study showed improvements in the qualities of lives among most of the related domains.

It is found that both the personal incomes and employment rates did not decrease after the kidney donations. With regarding the relationships of the living donors, the majority of

them belonged to first degree relationships to their recipients and represented 75 percent. When Crosstabs Analysis was used to analyze the relationships between the living kidney donors and their organ recipients of different ethnics, Chinese ethnic is found predominant among living kidney donors, but not Malay ethnic which donations rates are similar to the Indian ethnic, even though Malay is the major population in the country, which suggests the importance of donation education among ethnics.

Descriptive analysis was also used to analyze the qualities of lives of the living donors, which include time periods, physical and psychosocial health conditions. It is found that the peak of donations period was the years of 2005~2009 and it is decreased before and after the time period. For physical health conditions, the majority (92.6 percent) of the donors did not have major limit or incapability of their physical conditions and pain interfere of normal work. As the consequences, more than 76 percent of donor respondents had good, very good or excellent health after donations which indicating that the majority of the kidney donors are living their healthy lives post organ donations.

With regarding psychosocial health conditions, the majority (56.6 percent) of the donors felt calm and peaceful in their life; 50 percent of them had energy at most or all of the time; the majority did not have major limit or problem of their emotional health conditions; and 40 percent of the donor respondents never felt downhearted and depressed. But the majority did not have physical health or emotional problems interfering with their social activities. These results show that the psychosocial health conditions remain to be improved.

When the donor respondents were asked about their willing of re-donations, 67 percent of them would donate their kidneys again; and 97.5 percent did not regret their decisions of

donations; 93.8 percent agreed that the donations have made their lives more meaningful, 92.5 percent said the donations have made them respected in their families, and 93.8 percent said the donations improved their relationships with their recipients. 96.3% percent said they would strongly encourage other people to donate their organs.

For those questionnaires about government policies, 80 percent of the donor respondents thought that the government should set up clinics for donors, 88.8 percent thought that all donors should be systematically registered and monitored as of living donor registry, and 67.5 percent disagreed to being considered or treated as patients.

Inferential analysis of significant relationships shows that the healthier the living kidney donors were, the healthier the kidney recipients would be which indicating that healthy organ donations are one of the important factors for successful kidney transplantations. In addition, the comparison analysis for significant differences shows that the monthly incomes and employment rates were significantly higher after donations which show that the living kidney donations did not hurt their working and socialization abilities. It also shows that genders have no impact on the emotional health problems of daily activities from living donors.

As summary, the analyzed data show the following three major conclusions: firstly, the qualities of lives of living kidney donors have been improved after organ donations; secondly, the living capabilities of the living kidney donors did not decrease but were maintained indicating that living donations should be encouraged and promoted among the Malaysian populations, and these data can be used to educate people in the country to have better confidences and stronger potencies to kidney donations; thirdly, the results suggest

that the enhancements and set-up of government policies and donor specific registry systems are necessary for helping living kidney donors to receive knowledge and financial supports from the society, and well control their social activities after organ donations which will promote donor educations and improve donation awareness among regular populations.

5.4 RECOMMENDATIONS

Even though data obtained from the analysis show that living kidney donors are having good qualities of lives and should be recommended for potential populations, the living donor situations are still missing strong supports from the society and the government, and the quality of life as well as living donation rates remained to be improved when compared to other countries especially to those top living organ donation counties.

As the knowledge, there is no currently full scale of analysis reported of donor quality of life as it has been done in Malaysia, and more analyses with bigger scales and deeper explorations into the quality of life of living kidney donors must be conducted to offer knowledge and solutions to the improvements of the living donation situations when comparing to other countries of the world. To reach this goal, additional governmental policies and living kidney donor registry systems must be set up in Malaysia to fully support further studies and living donors' lives.

There are plenty of work to do before the country can have a relatively acceptable living kidney donation system to do more studies and explore deeper into the complex aspects of donations, which include decision making, donor and family relationship, donor and

recipient relationship, donor emotional and physical evaluations pre and post donations, etc. These explorations of quality of life of living donors require a fully set up donor registry system and fully support from government policies.

It will be a long way to go for Malaysia to finally reach the living donor organization settings of the European countries and the US, but action must be taken right now to protect the quality of life of living donor in order to enhance the world-lowest organ donation rate in the country. Since kidney is the most needed and most transplanted organ, it is here in this proposal strongly promoting the government to at least take one necessary action, to establish and implement live kidney donor registry with policies to protect the quality of life of living kidney donor in the country.

In summary, this chapter is strongly proposing a live donor kidney registry with policies to protect quality of life for living organ donor to be initiated and eventually implemented in Malaysia, which is one of the two important actions to be taken of the improvement of organ donation surgery and the implementation of policies to guarantee the quality of life of living kidney donors. This is urgently needed to protect living donors' lives and to promote increasing numbers of future living donors in this country. An open, simple and easy means to use living kidney donor registry with policies to protect the quality of life of living donors could be a rapid and effective solution to the current problematic situation. The system will help living donor to have better accesses to medical insurances, to receive financial aids from the government and local organizations, to share and receive information of organ donations, and to be organized for better performances in organ donations. If the efforts are made, a better future of living kidney donation is awaited in front of us.

REFERENCES

- Alex He Jingwei, Allen Lai Yu-Hung, Leong Ching. Living Organ Transplantation Policy Transition in Asia: Towards Adaptive Policy Changes. 2010. Global Health Governance, Volume III, No. 2.
- Bia MJ, Ramos EL, Danovitch GM, Gaston RS, Harmon WE, Leichtman AB et al. Evaluation of Living Renal Donors: The Current Practice of US Transplant Centers. Transplantation 1995; 60: 322-7.
- Byung Joo Jeon, In Gon Kim, Youl Keun Seong, Bo Hyun Han. Analysis of the Results of ABO-Incompatible Kidney Transplantation: In Comparison with ABO-Compatible Kidney Transplantation. 2010. Korean J Urol 2010;51:863-869.
- Clemens K, Boudville N, Dew MA, Geddes C, Gill JS, Jassal V, Klarenbach S, Knoll G, Muirhead N, Prasad GV, Storsley L, Treleaven D, Garg AX; Donor Nephrectomy Outcomes Research Network. The Long-term Quality of Life of Living Kidney Donors: A Multicenter Cohort Study. Am J Transplant. 2011 Mar;11(3):463-9.
- Crowley-Matoka M, Switzer G. Nondirected. Living Donation: A Survey of Current Trends and Practices. Transplantation 2005; 79, 515-519.
- De Groot IB, Stiggelbout AM, van der Boog PJ, Baranski AG, Marang-van de Mheen PJ; PARTNER-Study Group. Reduced Quality of Life in Living Kidney Donors: Association with Fatigue, Societal Participation and Pre-Donation Variables. Transpl Int. 2012 Sep;25(9):967-75.
- Delmonico FL, Domínguez-Gil B, Matesanz R, Noel L. A Call for Government Accountability to Achieve National Self-Sufficiency in Organ Donation and Transplantation. Lancet. 2011; 378(9800): 1414-8.
- Dutch Transplant Foundation. NTS. www.transplantatiestichting.nl
- Etzioni, Amitai. 2003. Organ Donation: A Communitarian Approach. Kennedy Institute of Ethics Journal Vol-13, No. 1, 1-18. The John Hopkins University.
- Fellner CH; Schwartz SH. Altruism in Disrepute: Medical Versus Public Attitudes Toward the Living Organ Donor. *New Eng J Med*. 1971;284:582-585.
- Fong L.F. Not Enough Kidney Donors in Malaysia. Asia News Network, July 2011. URL:<http://sg.news.yahoo.com/not-enough-kidney-donors-malaysia-051001208.html>

- Gerald S. Lipshutz, MD; Suzanne McGuire, RN; Qing Zhu, RN; Alyssa Ziman, MD; Rebecca Davis, MT(ASCP); Dennis Goldfinger, MD; Elaine F. Reed, PhD; Alan H. Wilkinson, MD; Gabriel M. Danovitch, MD; Phuong-Thu Pham, MD. ABO Blood Type-Incompatible Kidney Transplantation and Access to Organs. April 2011. ARCH SURG/VOL 146 (NO.4). American Medical Association.
- Gouge F, Moore J, Bremer BA, McCauly CR, Johnson JP. The Quality of Life of Donors, Potential Donors, and Recipients of Living-Related Donor Renal Transplantation. *Transplant Proc.* 1990;22:2409-2413.
- Henderson AJ, Landolt MA, McDonald MF, Barrable WM, Soos JG, Gourlay W et al. The Living Anonymous Kidney Donor: Lunatic or Saint? *Am J Transplant* 2003; 3, 203-213.
- Horvat LD, Shariff SZ, Garg AX; Donor Nephrectomy Outcomes Research (DONOR) Network. Global Trends in the Rates of Living Kidney Donation. *Kidney Int.* 2009; 75(10): 1088-98.
- Jacobs C, Johnson E, Anderson K, Gillingham K, Matas A. Kidney Transplants from Living Donors: How Donation Affects Family Dynamics. *Adv Renal Replace Ther.* 1998;5:89-97.
- Jacobs C. Psychosocial Process of Living Organ Donors. Paper presented at: Living Organ Transplantation: A National Consensus Conference; June 1-2, 2000; Kansas City, Mo.
- Jacobs CL, Roman D, Garvey C, Kahn J, Matas A. Twenty-two Nondirected Kidney Donors: An Update on a Single Center's Experience. *Am J Transplant* 2004; 4, 1110-1116.
- Johnson EM, Anderson JK, Jacobs C, et al. Long-Term Follow-Up of Living Kidney Donors: Quality of Life After Donation. *Transplantation.* 1999;67:717-721.
- Johnson EM, Anderson JK, Jacobs C, Suh G, Humar A, Suhr BD et al. Long-Term Follow-Up of Living Kidney Donors: Quality of Life After Donation. *Transplantation* 1999; 67: 717-21.
- Johnson EM, Remucal MJ, Gillingham KJ, Dahms RA, Najarian JS, Matas AJ. Complications and Risks of Living Donor Nephrectomy. *Transplantation* 1997; 64: 1124-8.
- Karrfelt HM, Berg UB, Lindblad FI, Tyden GE. To Be or Not To Be A Living Donor: Questionnaire to Parents of Children Who Have Undergone Renal Transplantation. *Transplantation.* 1998;65:915-918.
- Kasiske BL, Ravenscraft M, Ramos EL, Gaston RS, Bia MJ, Danovitch GM. The Evaluation of Living Renal Transplant Donors: Clinical Practice Guidelines. *J Am Soc Nephrol* 1996; 7: 2288-2313.

- Kassim PN. Organ Transplantation in Malaysia: A Need for A Comprehensive Legal Regime. *Med Law*. 2005; 24(1): 173-89.
- Klerk de M, Keizer K, Claas F, Witvliet, M, Haase-Kromwijk B, Weimar W. The Dutch National Living Donor Kidney Exchange Program. *Am J Transplant* 2005; 5, 2302-2305.
- Kok NF, Alwayn IP, Tran KT, Hop WC, Weimar W, IJzermans JN. Psychosocial and Physical Impairment After Mini-Incision Open and Laparoscopic Donor Nephrectomy: A Prospective Study. *Transplantation*. 2006; 82(10):1291-7.
- Kok NF, Lind MY, Hansson BM, Pilzecker D, Mertens zur Borg IR, Knipscheer BC. Comparison of Laparoscopic and Mini Incision Open Donor Nephrectomy: Single Blind, Randomised Controlled Clinical Trial. *BMJ* 2006; 333(7561): 221-6.
- Kok NF, weimar W, Alwayn IP, IJzermans JN. The Current Practice of Live Donor Nephrectomy in Europe. *Transplantation* 2006; 82(7): 892-7.
- Kroencke S, Fischer L, Nashan B, Herich L, Schulz KH. A Prospective Study on Living Related Kidney Donors' Quality of Life in the First Year: Choosing Appropriate Reference Data. *Clin Transplant*. 2012 Jul-Aug;26(4):E418-27.
- Lumsdaine JA, Wray A, Power MJ, Jamieson NV, Akyol M, Bradley AJ et al. Higher Quality of Life in Living Donor Kidney Transplantation: Prospective Cohort Study. *Transpl Int*. 2005 Aug;18(8):975-80.
- Mahari MZ. Demographic Transition in Malaysia. 2010. URL: http://www.cwsc2011.gov.in/papers/demographic_transitions/Paper_1.pdf
- Makmor Tumin, Abdillan Noh, Chong Chin Sieng, Kim Soo Kun, Nawi Abdullah, Ng Kok Peng. Strategies Targeted at Motivating Unrelated Living Kidney Donation. 2010.
- Makmor Tumin, Noh A, Kun LS, Abdullah N, Aung TT. Medical Benefits for Organ Donors: An Alternative Reimbursement Policy. 2011. *Experimental and Clinical Transplantation*.
- Makmor Tumin, Noh A, Sieng CC, Kun LS, Abdullah N, Peng NK. Can't Government Subsidize Fees for Medical Check-up? A Preliminary Study on Living Kidney Donors in Malaysia. Elsevier Editorial System™ for Transplantation Proceedings Manuscript.
- Manyalich M, Ricart A, Martínez I, Balleste C, Paredes D, Vilardell J, Avsec D, Dias L, Fehrman-Eckholm I, Hiesse C, Kyriakides G, Line PD, Maxwell A, Nanni Costa A, Paez G, Turcu R, Walaszewski J. EULID Project: European Living Donation and Public Health. *Transplant Proc*. 2009 Jul-Aug;41(6):2021-4.
- Mjøen G, Stavem K, Westlie L, Midtvedt K, Fauchald P, Norby G, Holdaas H. Quality of Life in Kidney Donors. *Am J Transplant*. 2011 Jun;11(6):1315-9.

"National Data Reports". The Organ Procurement and Transplant Network (OPTN). URL: <http://optn.transplant.hrsa.gov/latestData/step2.asp>

NATCO Living Donor Health Care Coverage, Insurability and Follow-up Position Statement. May 2006. Lenexa, KS.

Nazni Noordin, Zaherawati Zakaria, Adnan Aminuddin, Mahazril' Aini Yaacob, Mohd Zool Hilmie Mohamed Sawal, Mohd Shamsul Daud, Azrul Shahimy Mohd Yusof, Kamarudin Ngah. Organ Donation among Malaysian: The Malay Dilemma toward Social Development. 2012, Vol 8(10)

New Straits Times. 15,420 Malaysians on Organ Waiting List. August 13, 2012.

Nicholson ML, Elwell R, Kaushik M, Bagul A, Hosgood SA. Health-Related Quality of Life After Living Donor Nephrectomy: A Randomized Controlled Trial of Laparoscopic Versus Open Nephrectomy. *Transplantation*. 2011; 91(4): 457-61.

Ogutmen B, Yildirim A, Sever MS, Bozfakioglu S, Ataman R, Erek E et al. Health-Related Quality of Life After Kidney Transplantation in Comparison Intermittent Hemodialysis, Peritoneal Dialysis, and Normal Controls. *Transplant Proc*. 2006; 38(2):419-21.

O'Reilly KB. Prisoner Organ Donation Proposal Worrisome. *America Medical News*. April 9, 2007. URL: <http://www.ama-assn.org/amednews/2007/04/09/prsb0409.htm>

Orentlicher, D. Presumed Consent to Organ Donation: Its Rise and Fall in the United States. *Rutgers Law Review*. 2009, 61(2): 295.

Organ Transplantation From the Islamic Perspective. 2011. Ministry of Health Malaysia.

Paxman R. All Donor-Conceived People Should Have Access to Donor Information, Australian Committee Recommends. *BioNews*. April 2, 2012, URL: http://www.bionews.org.uk/page_137284.asp

Sadler HH; Davison L; Carroll C; Kountz SL. The Living, Genetically Unrelated, Kidney Donor. *Semin Psychiatry*. 1971;3:86-101.

Schover LR, Streem SB, Boparai N, Duriak K, Novick AC. The Psychosocial Impact of Donating A Kidney: Long-Term Follow-Up From a Urology-Based Center. *J Urol*. 1997;157:1596-1601.

Simmons RG, Klein Marine S, Simmons RL. Gift of Life: The Effect of Organ Transplantation on Individual, Family, and Societal Dynamics. New York, NY: Transaction Books; 1987.

- Smith M, Kappell D, Province M, et al. Living-Related Kidney Donors: A Multicenter Study of Donor Education, Socioeconomic Adjustment, and Rehabilitation. *Am J Kidney Dis*. 1986;8:223-233.
- Spital A. Increasing The Pool of Transplantable Kidneys Through Unrelated Living Donors and Living Donor Paired Exchanges. *Semin Dial*. 2005;18(6):469-73.
- Spooner MH. More Countries Hoping to Copy Spain's Organ-Donation Success. *Canadian Medical Association Journal*. 2003 October 28; 169(9): 952.
- Stichting Renine, Registratie Nierfunctieervanging Nederland. <http://www.renine.nl>
- Switzer GE, Dew MA, Twillman RK. Psychosocial Issues in Living Organ Donation. In Trezpacz P, DiMartini A, eds. *The Transplant Patient: Biological, Psychiatric and Ethical Issues in Organ Transplantation*. Cambridge, England: Cambridge University Press; 2000:42-66.
- Terasaki PI, Cecka JM, Gjertson DW, Cho YW. Spousal and Other Living Renal Donor Transplants. *Clin Transplan* 1997, 269-284.
- Terasaki PI, Cecka JM, Gjertson DW, Takemoto S. High Survival Rates of Kidney Transplants from Spousal and Living Unrelated Donors. *N Engl J Med* 333(6); 333-336.
- The Borneo Post Online, 15,000 Waiting for Organs to be Donated. May 19, 2012. <http://www.theborneopost.com/2012/05/19/15000-waiting-for-organs-to-be-donated/>
- The Quality of Life of Living Donors: Reviews of Short Form -36 surveys
- The United States National Kidney Registry. URL: http://www.kidneyregistry.org/living_donors.php?cookie=1
- Thiel, G. Emotionally Related Living Kidney Donation: Pro and Contra. *Nephrol Dial Transplant* 1997;12, 1820-1824.
- Tong A, Chapman JR, Wong G, Kanellis J, McCarthy G, Craig JC. The Motivations and Experiences of Living Kidney Donors: A Thematic Synthesis. *Am J Kidney Dis*. 2012 Jul;60(1):15-26.
- Toronyi E, Alföldy F, Jaray J, et al. Attitudes of Donors toward Organ Transplantation in Living Related Kidney Transplantations. *Transpl Int*. 1998;11(suppl 1):S481-483.
- Unrelated Living Organ Donation: Policy and Procedures. 2011. Transplantation Unit, Ministry of Health Malaysia.
- Vemuru Reddy SK, Guleria S, Okechukwu O, Sagar R, Bhowmik D, Mahajan S. Live Related Donors in India: Their Quality of Life Using World Health Organization Quality of Life Brief Questionnaire. *Indian J Urol*. 2011 Jan;27(1):25-9.

- Weng LC, Huang HL, Wang YW, Chang CL, Tsai CH, Lee WC. The Coping Experience of Taiwanese Male Donors in Living Donor Liver Transplantation. *Nurs Res.* 2012 Mar-Apr;61(2):133-9.
- Westlie L, Fauchald P, Talseth T, Jakobsen A, Flatmark A. Quality of Life in Norwegian Kidney Donors. *Nephrol Dial Transplant* 1993; 8: 1146-50.
- Westlie L, Fauchald P, Talseth T, Jakobsen A, Flatmark A. Quality of life in Norwegian Kidney Donors. *Nephrol Dial Transplant.* 1993;8:1146-1150.
- WHO Guiding Principles on Human Organ Transplantation Report of the Regional Meeting. June 8 – 10, 2009. Kuala Lumpur, Malaysia.

APPENDIX 1

Please answer all the questions.

Section A: Background of Respondent
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Please tick (✓) your answer accordingly.

(1) Gender:

☐ Male ☐ Female

(2) Ethnic:

☐ Malay ☐ Indian
☐ Chinese ☐ Others (please specify): _____

(3) Marital Status:

☐ Single
☐ Married
☐ Widow/Divorced

(4) Highest education achievement:

☐ Primary school
☐ Secondary school
☐ Tertiary
☐ Others (please specify): _____

(5) Monthly Income:

(Please tick [✓] both: your current income and your income at the time of donation)

	Current	At the time of donation
None*	<input type="checkbox"/>	<input type="checkbox"/>
Less than RM1,000	<input type="checkbox"/>	<input type="checkbox"/>
RM1,000 - RM2,000	<input type="checkbox"/>	<input type="checkbox"/>
RM2,001 - RM3,000	<input type="checkbox"/>	<input type="checkbox"/>
RM3,001-RM4,000	<input type="checkbox"/>	<input type="checkbox"/>
Above RM4,000	<input type="checkbox"/>	<input type="checkbox"/>

* If you have no income, how do you survive?

Before donating your kidney:

- ☐ Supported mainly by family
☐ Supported mainly by the recipient
☐ Supported mainly by charity organization(s)
☐ Supported mainly by my own saving
☐ _____ Others (please specify):

After donating your kidney:

- ☐ Supported mainly by family
☐ Supported mainly by the recipient
☐ Supported mainly by charity organization(s)
☐ Supported mainly by my own saving
☐ _____ Others (please specify):

(6) Employment Status:

(Please tick [V] both: your current employment status and your employment status at the time of donation)

	Current	At the time of donation
Housewife/Househusband	<input type="checkbox"/>	<input type="checkbox"/>
Unemployed	<input type="checkbox"/>	<input type="checkbox"/>
Self-employed	<input type="checkbox"/>	<input type="checkbox"/>
Public sector employee	<input type="checkbox"/>	<input type="checkbox"/>
Private sector employee	<input type="checkbox"/>	<input type="checkbox"/>
NGO/Charitable organization	<input type="checkbox"/>	<input type="checkbox"/>
Others (please specify):	<input type="checkbox"/>	<input type="checkbox"/>

(7) Relationship with organ recipient:

(a) Genetically related:

- ☐ First degree relative (mother, father, daughter, son, sibling)
☐ Second degree relative (grandmother, grandfather, granddaughter, grandson, aunt, uncle, niece, nephew, half sister, half brother)
☐ Third degree relative (a distant relative)

(b) ☐ Emotionally related

(c) ☐ Others (please specify): _____

(8) Age:

Current: _____ years

At the time of donation: _____ years

Section B: Psychosocial and Physical Health (Quality of Life)

(1) When did you donate your organ?

Year: _____

(2) In general, would you say your health is:

[] Excellent [] Very good [] Good [] Fair [] Poor

(3) The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? Please tick [☒] your answer.

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf			
b. Climbing several flights of stairs			

(4) During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health? Please tick [☒] your answer.

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Accomplished less than you would like					
b. Were limited in the kind of work or other activities					

(5) During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
(a) Accomplished less than you would like					
(b) Did work or activities less carefully than usual					

Section C: Statement of Donation

(1) For the following questions, please tick [√] “Yes” or “No.”

(a) If it were possible, I would donate my kidney again

[] Yes [] No

(b) I would strongly encourage others to donate their organ

[] Yes [] No

(c) I regretted my decision to donate my organ

[] Yes [] No

(d) Donation makes my life more meaningful

[] Yes [] No

(e) Donation improved my relationship with the recipient

[] Yes [] No

(f) Donation makes me more respected in the family

[] Yes [] No

Section D: Support after Donation
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(1) For the following statements, please tick [✓] “Yes” or “No” or “Undecided”

(a) I should be considered/treated as a patient too

[] Yes [] No [] Undecided

(b) The government should set-up clinics for donors

[] Yes [] No [] Undecided

(c) All donors should be systematically registered and monitored (living donors registry)

[] Yes [] No [] Undecided