ACCESS TO RENAL TRANSPLANTATION AND POST-TRANSPLANTATION PROGNOSIS (ReTRAPP) STUDY OF ADULTS IN MALAYSIA

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ABSTRACT

Introduction

Renal transplantation (RT) is recognised as the preferred treatment modality for end-stage renal disease. However, Malaysian transplantation rates have been low compared to other countries. Numerous clinical determinants have been associated with renal transplant recipient' (RTRs) health, which is the main focus of the healthcare fraternity. Coincident with the rising interest for equitable healthcare, many studies in the high-income countries have examined the disparities in RT. On the contrary, little is known about the association of socioeconomic gradient of RTRs on the access and outcome of RT in Malaysia, a low- and middle-income country. ReTRAPP was designed to explore the factors that limit access as well as assess the association of socioeconomic status (SES) on the access and outcome (survival rate, quality of life and financial burden) of RT.

Methodology

Collection of *qualitative data* involved semi-structured interviews with eight key-informants, who are identified by detailed stakeholder analysis. Their responses were used to explore current RT policy and service availability and to identify relevant themes.

Quantitative data examined from the National Renal Registry of Malaysia for RTRs above 18 years between 2002 and 2011 (n=1234 recipients).Cox's regression was used to evaluate the association of SES on access to RT and post-transplantation survival rate.

A quantitative study using a survey was administered to 409 RTRs in 6 public health facilities in Greater Kuala Lumpur. Linear regression was used to determine the association of SES on quality of life and logistic regression for association of SES and catastrophic health expenditure (CHE).

Results

The in-depth interviews are categorised and described by the socio-ecological model, which provided a framework better to understand the barriers and solutions to RT in Malaysia. Results from the thematic analysis illustrate a complex interplay of personal, cultural, and environmental factors. Lower household income was associated with reduced access to renal transplantation (adjusted $P_{Trend} = 0.001$). Additionally, patients with higher educational attainment have a better survival rate post-transplantation (adjusted $P_{Trend} < 0.001$). Mean scores for all WHOQOL domains were reduced for RTRs with low SES compared to high SES. After multivariable adjustment, educational attainment and household income continued to affect all WHOQOL domains significantly. 22.7% of RTRs experience CHE due to post-transplantation care. Household income is the only SES indicator to show statistical significance with Middle 40% household income group and Bottom 40% household income group having 4.7 times and 5.3 times more risk for CHE.

Conclusion

ReTRAPP was conducted to explore the barriers that limit RT and evaluate the social inequalities in access and outcome of RT. Specific barriers and solutions highlighted in ReTRAPP indicate a need for policy change in the health service delivery model to improve the RT rate. ReTRAPP further highlights the disparities in access and post-transplantation care of RTRs. These findings provide healthcare leaders with opportunities to reduce disparities through a better understanding of the delivery of care. Considering the impact of socioeconomic differentials on disparities in healthcare, a multidiscipline partnership from various stakeholders is necessary to address the socioeconomic inequality in access to care and health outcomes for RTRs.

Keywords Renal Transplantation, Socio-Economic Status, Access to Renal Transplantation, Outcome of Renal Transplantation, Malaysia

ABSTRAK

Pengenalan

Pemindahan buah pinggang (PBP) diiktiraf sebagai modaliti rawatan pilihan untuk penyakit buah pinggang peringkat akhir. Walau bagaimanapun, kadar pemindahan Malaysia telah rendah berbanding negara lain. Sejumlah penentu klinikal telah dikaitkan dengan kesihatan penerima pemindahan buah pinggang (PPBP), yang merupakan tumpuan utama dalam persaudaraan penjagaan kesihatan. Kebetulan dengan peningkatan minat untuk penjagaan kesihatan yang saksama, banyak kajian di negara berpendapatan tinggi telah meneliti kesenjangan di PBP. Sebaliknya, sedikit diketahui mengenai persatuan kecerunan sosioekonomi PPBP mengenai akses dan hasil PBP di Malaysia, negara berpendapatan rendah dan sederhana. ReTRAPP direka untuk meneroka faktor-faktor yang menghadkan akses dan menilai persatuan status sosioekonomi (SSE) mengenai akses dan hasil (kadar survival, kualiti hidup dan beban kewangan) PPBP.

Metodologi

Pengumpulan data kualitatif melibatkan wawancara separuh berstruktur dengan lapan informan, yang dikenal pasti oleh analisis pemangku kepentingan terperinci. Tanggapan mereka digunakan untuk meneroka dasar PBP dan ketersediaan perkhidmatan semasa dan mengenal pasti tema yang relevan.

Pengumpulan data kuantitatif dengan memeriksa Pendaftaran Buah Pinggang Negara Malaysia untuk PPBP melebihi 18 tahun antara 2002 dan 2011 (n = 1234 penerima). *Cox's regression* digunakan untuk menilai persatuan SES mengenai akses ke PBP dan kadar survival selepas pasca pemindahan.

Kajian kuantitatif yang menggunakan kaji selidik diberikan kepada 409 PBP di 6 fasiliti kesihatan awam di Kuala Lumpur. *Linear regression* digunakan untuk menentukan perhubungan SSE dengan kualiti hidup dan *logistic regression* untuk perhubungan SSE dengan perbelanjaan kesihatan bencana (BKB).

Keputusan

Wawancara mendalam dikategorikan dan dijelaskan oleh model sosio-ekologi, yang memberikan kerangka yang lebih baik untuk memahami halangan dan penyelesaian PBP di Malaysia. Hasil dari analisis tematik menggambarkan interaksi kompleks faktor peribadi, budaya, dan persekitaran. Pendapatan isi rumah yang rendah dikaitkan dengan pengurangan akses untuk pemindahan buah pinggang (*Adjusted* P_{Trend} = 0.001). Selain itu, pesakit dengan pencapaian pendidikan tinggi mempunyai kadar kelangsungan hidup yang lebih baik selepas transplantasi (*Adjusted* P_{Trend} <0.001). Skor min untuk semua domain WHOQOL dikurangkan untuk PPBP dengan SSE rendah berbanding SSE tinggi. Selepas penyesuaian berbilang variabel, pencapaian pendidikan dan pendapatan isi rumah terus mempengaruhi semua domain WHOQOL dengan ketara. 22.7% PPBP mengalami BKB kerana rawatan pasca transplantasi. Pendapatan isi rumah adalah satu-satunya indikator SSE yang menunjukkan kepentingan statistik dengan kumpulan pendapatan isi rumah Tengah 40% dan kumpulan pendapatan isi rumah bawah 40% mempunyai risiko 4.7 kali dan risiko 5.3 kali ganda untuk BKB.

Kesimpulannya

ReTRAPP telah dijalankan untuk meneroka halangan yang membatasi PBP dan menilai ketidaksamaan sosial dalam akses dan hasil PBP. Halangan dan penyelesaian khusus yang diketengahkan dalam ReTRAPP menunjukkan keperluan perubahan dasar dalam model penyampaian perkhidmatan kesihatan untuk meningkatkan kadar PBP. ReTRAPP selanjutnya menonjolkan kesenjangan dalam penjagaan dan penjagaan pasca pemindahan pemindahan PPBP. Penemuan ini memberi para pemimpin penjagaan kesihatan peluang untuk mengurangkan kesenjangan melalui pemahaman yang lebih baik tentang penyampaian penjagaan. Memandangkan kesan perbezaan sosioekonomi terhadap ketidaksamaan dalam penjagaan kesihatan, perkongsian pelbagai disiplin dari pelbagai pihak berkepentingan perlu untuk menangani ketidaksamaan sosioekonomi dalam akses kepada penjagaan dan hasil kesihatan untuk PPBP.

Kata kunci: Pemindahan Buah Pinggang, Status Sosioekonomi, Akses kepada Pemindahan Buah Pinggang, Hasil Pemindahan Buah Pinggang, Malaysia

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To my dearest friends,
for being there.

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LIST OF ABBREVIATIONS

ANZDATA	Australian and NZ Dialysis and Transplant Registry
AV	Arteriovenous
CHE	Catastrophic Health Expenditure
CKD	Chronic Kidney Disease
CT	Computerise Tomography
CVI	Content Validity Index
DAT	Donor Advocate Team
DMV	Department of Motor Vehicle
EPF	Employee Provident Fund
ESRD	End-Stage Renal Disease
GCP	Good Clinical Practice
GDP	Gross Domestic Product
GFR	Glomerular Filtration Rate
HD	Haemodialysis
HKL	Kuala Lumpur Hospital
HR	Hazard Ratio
IBM	International Business Machines
ICH	International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use
ICU	Intensive Care Unit
ILO	International Labour Organization
KCD	Kidney Chain Donation
KL	Kuala Lumpur
MC	Medical Certificate
MDTR	Malaysian Dialysis and Transplant Registry
MICE	Multiple Imputation Chained Equation
MMC	Malaysian Medical Council
MNS	Malaysian Nephrology Society
MOE	Ministry of Education
MOH	Ministry of Health
MOSS	Malaysian Organ Sharing System
MREC	Medical Research & Ethics Committee

MRI	Magnetic Resonance Imaging
NTRC	National Transplant Resource Centre
NCD	Non-Communicable Diseases
MHS	National Health Service
NRR	National Renal Registry
ODT	Organ Donation and Transplantation
OOP	Out-of-Pocket
OT	Operation Theatre
QOL	Quality of Life
PD	Peritoneal Dialysis
PMM	Predictive Mean Matching
ReTRAPP	Access to Renal Transplantation and Post-Transplantation Prognosis Study of Adults in Malaysia
RRT	Renal Replacement Therapy
RTRs	Renal Transplant Recipients
SEM	Socio-Ecological Model
SES	Socioeconomic Status
SF-36	36-Item Short-Form Health Survey
SOCSO	Social Security Organization
SPM	Social and Preventive Medicine
SPSS	Statistical Package for the Social Sciences
TOP	Tissue Organ Procurement
TPMU	Transplantation Procurement Management Unit
Tx	Transplantation
UHC	Universal Health Coverage
UMMC	University of Malaya Medical Centre
UKMMC	University Kebangsaan Malaysia Medical Centre
UK	United Kingdom
USA	United States of America
UTAC	Unrelated Transplant Approval Committee
WHA	World Health Assembly
WHO	World Health Organization
WHOQOL - BREF	World Health Organization Quality of Life Instrument

LIST OF APPENDICES

CHAPTER 1: INTRODUCTION

This study, Access to Renal Transplantation and Post-Transplantation Prognosis (ReTRAPP) of Adults in Malaysia, was developed after perusing the many health issues that dominated the headlines. We constructed the ReTRAPP framework after multiple discussions with key opinion leaders of renal transplantation. The primary concern of ReTRAPP stems from low renal transplantation rate (H. S. Wong & Goh, 2018). Despite numerous national initiatives executed throughout the years ranging from organ donation drive to create awareness of organ donation to the establishment of National Kidney Transplant Centre and National Transplant Resource Centre.

The opening chapter will provide a brief contextual background on the disease affecting many patients that requires them to receive renal replacement therapy and why is renal transplantation the preferred treatment option. It will also introduce the concept of patient's socioeconomic status influencing the access as well as the outcome of renal transplantation which is the overarching theme of ReTRAPP. The final section briefly explains the significance of ReTRAPP in the context of Malaysia.

1.1 End-Stage Renal Disease

End-stage renal disease (ESRD) is the final stage of chronic kidney disease characterised by the irreversible deterioration of renal function, whereby the kidneys would progressively lose its function to remove waste product from the body. Initially, renal failure is asymptomatic and manifest itself as a biochemical abnormality on laboratory investigation. Eventually, signs and symptoms of ESRD would be evident and worsen, which would lead to a condition referred to as uraemia (Chikotas et al., 2006).

ESRD is a life-threatening condition that requires renal replacement therapy (RRT) to remove the waste and excess fluid from the body. The worldwide prevalence of ESRD patients requiring maintenance dialysis was approximately 284 per 1 million population in 2010, which represents about 2 million ESRD patients (B. Thomas et al., 2015). While for Malaysia, the number of ESRD patients requiring maintenance dialysis was four folds the global figures with 830 per 1 million population which translate to about 23700 ESRD patients (H. S. Wong & Goh, 2018).

The social and economic consequences of ESRD are considerable. With a four-fold increase of morbidity and mortality as compared to the general public (Saran et al., 2018). ESRD is essential and yet "neglected" non-communicable disease that has become a significant public health priority on the policymakers' agenda. As the prevalence of ESRD patients in Malaysia is projected to increase to 100 000 in 2040 (Bujang et al., 2016), so will the financial burden to treat these patients. Furthermore, Bujang et al. predicted that it would cost ten times more to treat ESRD patients who are on dialysis in 2040 as compared to 2000 (Bujang et al., 2016). It will impose a substantial financial burden on ESRD patients, especially in low- and middle-income countries where family members will experience direct loss of income and reduced household expenditure to spend on healthcare. High-income countries spend about 2–3% of the healthcare budget to provide treatment for ESRD patients even though they only represent 0.1–0.2% of the total population (Jha et al., 2013).

1.2 Renal Transplantation

Renal transplantation is considered the preferred treatment of choice for end-stage renal disease (ESRD) patients when compared to other forms of renal replacement therapy (RRT) like haemodialysis (HD) or peritoneal dialysis (PD). Many studies conducted either locally (Bavanandan et al., 2015) or abroad have demonstrated a better long-term survival rate (as demonstrated by Figure 1.1). It also showed to have a better quality of life (Junchotikul et al., 2015; H. Lim et al., 2016; Maglakelidze et al., 2011; Ogutmen et al., 2006) for renal transplant recipients (RTRs) when compared to dialysis. Renal transplant recipients aged 20–39 years in the United States of America have two times higher rate of survival compared to ESRD patients who are on the waiting list (Kaballo et al., 2017). It was estimated that renal transplant recipients live 17 years longer than ESRD patients on the waiting list for the same age group (Wolfe et al., 1999). More and more studies have also proven that renal transplantation has a better economic advantage compared to dialysis with costs of transplantation decreasing while the cost of dialysis continuing to increase (Cavallo et al., 2014; Eriksson et al., 2016; Haller et al., 2011; Rosselli et al., 2015).

The allocation of a deceased donor kidney is based on the policies established by the Ministry of Health Malaysia under the National Organ, Tissue and Cell Transplantation Policy 2007, Nephrology Services Operational Policy 2011. It determined that the individual with the greatest need for renal transplantation should be allocated a deceased donor kidney. While for the living-related donor kidney, any family member who wishes to donate his/her kidney to the ESRD patient will be able to do so after assessment by the transplant team before proceeding with the surgery. On the other hand, The Unrelated Living Organ Donation: Policy and Procedures 2011 governs the living-unrelated kidney donation, which details how living renal donations are managed.

According to the National Renal Registry, a total of 39,711 ESRD patients were on dialysis in 2016 and out of this cohort, it was estimated that 20,000 patients were eligible for renal transplantation (H. S. Wong & Goh, 2018). However, during the same year, only 82 renal transplantations were recorded by the registry which included 50 local renal transplants and 32 commercial renal transplants showing that the number ESRD patients requiring renal transplantation far outweigh the number of renal donors available for transplantation. Despite strong evidence to support renal transplantation as the best renal replacement therapy modality, the transplantation rate in Malaysia remains low.

Previous studies have shown that inequities exist in access to renal transplantation. The evidence for this is mainly from high-income countries. It revealed that there is an association between renal transplantation and ethnicity (Hall et al., 2012; Ravanan et al., 2010), gender (S Bayat et al., 2015; Neri et al., 2013), socioeconomic status (SES) (Axelrod et al., 2010; Grace et al., 2013; Y. Zhang et al., 2017), marital status (Khattak et al., 2010), and geographical location (Axelrod et al., 2014; Mathur et al., 2010). The rates of renal transplantation vary internationally, and severe global inequities in access to renal transplantation exist between and within countries (Garcia et al., 2012).

Low and middle-income countries often display reduced renal transplant rates. It is due to multiple medical factors (e.g. haemoglobin level, immunological matching and co-morbid diseases) and non-medical factors (e.g. patient socioeconomic status, medication adherence, access to care, inadequate infrastructure and insufficiently trained healthcare workers) affecting ESRD patients. While most low- and middle-income countries account for less than 20% of treated ESRD patients with a renal transplant, in-centre haemodialysis (HD) was the predominant RRT modality (Saran et al., 2018). This situation is worsened by deceased donation rates underpinned by the lack of a legal framework governing organ donation. On top of that, local religious, cultural and social

practices play an integral role in the daily lives of the community of low- and middle-income countries which further discourage organ donation (Irving et al., 2011). Figure 1.1 shows a significant contrast of lower renal transplant rates for Malaysia (middle-income country) compared to the high-income countries globally.

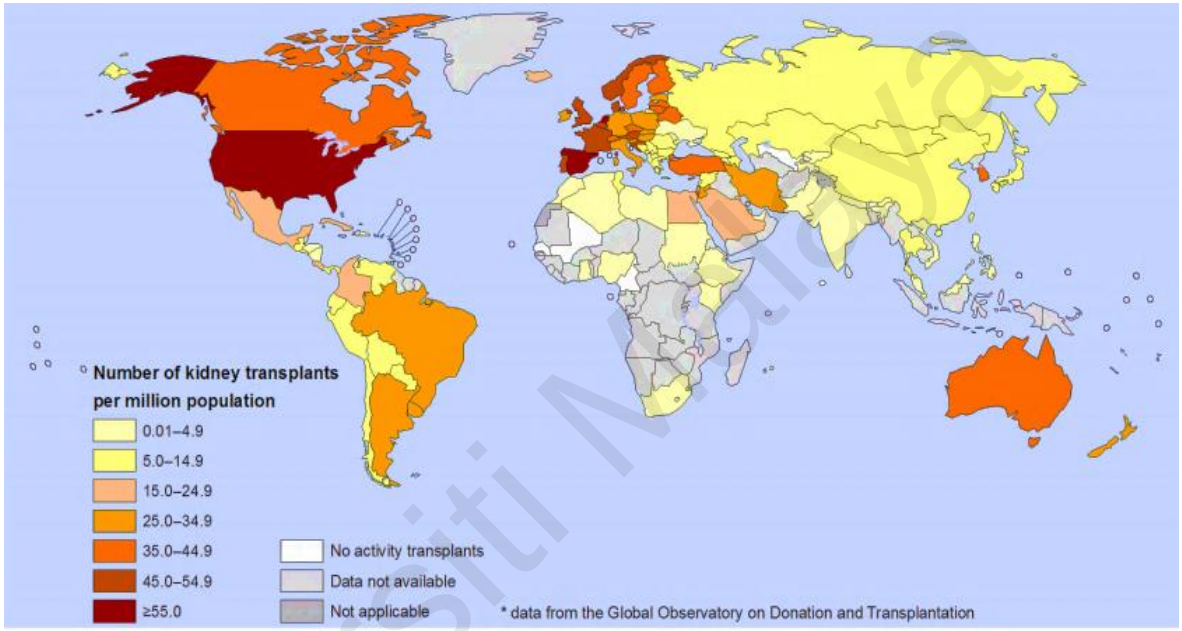


Figure 1.1: Malaysia's renal transplant activities compared to other countries
Source: (European Directorate for the Quality of Medicines & HealthCare of the Council of Europe, 2017)

1.3 Framing the Problem

The majority of the studies that were conducted in high-income countries focus on racial and ethnic disparities in access to renal transplantation (Arce et al., 2013; Joshi et al., 2013; Mucsi et al., 2017; Tjaden et al., 2016) and its effect on the outcome (Lentine et al., 2014; Taber et al., 2014; Tjaden et al., 2016). However, one of the notable gaps that stood out from the non-clinical perspective of renal transplantation research would be the limited literature that is available on the influence of SES of the ESRD patients on the outcome and access of renal transplantation.

SES plays an integral role in the renal transplantation process, and the information gathered from research conducted in high-income countries suggest that it is a significant factor for renal transplantation (Axelrod et al., 2010; Hod & Goldfarb-Rumyantzev, 2014). Different studies using a different interpretation of SES conducted in various high-income countries with diverse healthcare and educational systems indicates that population with high SES increases the chances of access to renal transplantation. Despite these findings from high-income countries, studies examining the impact of SES on process and outcomes in renal transplantation are severely lacking especially in low and middle-income countries.

As mentioned earlier, renal transplantation may not be a priority in low and middle-income countries due to the lack of resources (e.g. infrastructure and workforce). Besides, the survival of the renal transplant recipient is complicated by the accessibility and affordability of immunosuppressive drugs, malnutrition and infectious disease (Verma et al., 2000). However, renal transplantation could be the modality of choice promoted by the government to treat ESRD. An example of a success story of a middle-income country that prioritised renal transplantation, Costa Rica was able to provide renal transplant to 56% of its ESRD population in 2002, which was among the highest in the Latin America (Cerdas, 2005). Like Malaysia, Costa Rica has almost achieved universal health coverage (UHC), which covers about 98% of the population by providing access to RRT. Still, Costa Rica promotes renal transplantation while Malaysia is heavily dependent on dialysis as a modality. Its contrast is illustrated in Figure 1.2 on the proportion of overall RRT made up by renal transplantation by Gross Domestic Product (GDP) per capita in 2002. Even though there was the availability of RRT service, especially renal transplantation in Costa Rica, the accessibility to RRT was restricted by socioeconomic factors (Cerdas, 2005).

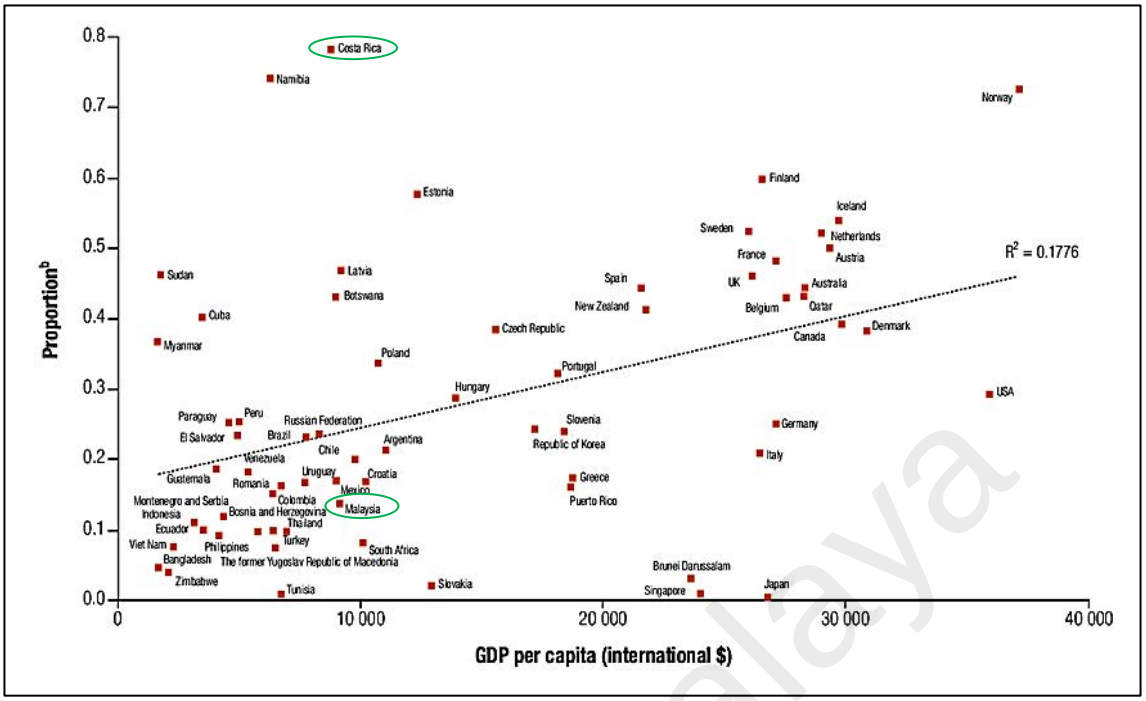


Figure 1.2: Proportion of overall RRT made up by renal transplantation by GDP per capita for 2002

Source: (White, Chadban, Jan, Chapman, & Cass, 2008)

Note

Both Malaysia and Costa Rica have similar GDP per capita. Still, Malaysia's proportion of expenditure on renal transplantation makes up less than 20% of total RRT spending while Costa Rica spends about 80%.

RRT – renal replacement therapy

GDP – gross domestic product

International $ – US dollar

Although the data represented from Figure 1.2 was from 2002, it is still relevant currently. The percentage ESRD patients that were on dialysis in 2002 were at 84.1% with 15.9% had undergone renal transplantation (Goh et al., 2012), while the trend for 2015 reported 95.1% of patients were on dialysis with only 4.9% received renal transplantation (H. S. Wong & Goh, 2016). This demonstrates that despite promotion of renal transplantation there has not been a positive impact on the renal transplant rate in Malaysia. With the exponential increase in the number of ESRD patients, renal

transplantation would be the preferred treatment of choice for these patients. However, this is not the case for Malaysia.

The role of SES on renal transplantation is complex because SES affects healthcare provision and uptake along the pathway to transplantation. Coupled with minimal research on renal transplantation, Malaysia and other low and middle-income countries, infrequently contribute to the pool of information on the social determinants of health for the ESRD patients, especially for renal transplantation. Therefore, by understanding the significance of SES on renal transplantation, ReTRAPP would provide valuable knowledge for clinicians and policymakers to facilitate the varying social needs that affect the clinical outcomes of the renal transplant recipients. Despite the mounting evidence of SES-related inequalities in renal transplantation, the relative influence of SES factors remains poorly understood. Most of the studies conducted have focused on medical treatment-related factors, while healthcare providers and system-related factors are still not well explored, especially in qualitative studies.

As Malaysia inches closer to achieving high-income nation status, there is a need to ensure that the healthcare system can deliver quality services to improve the health of ESRD patients on par with other high-income countries. The healthcare system must ensure that there are no disparities for ESRD patients to access renal transplantation and equity in the delivery of care for all renal transplant recipients.

1.4 Malaysia's Sociodemographic Background

Malaysia is a culturally, ethnically and linguistically diverse society made up of two regions that are separated by the South China Sea. Malaysia is a constitutional monarchy consisting of 13 states and three federal territories. As of mid-2018, the population stood at 32.4 million, out of which 29 million are Malaysians (Department of Statistics Malaysia, 2018c) which mainly consist of Bumiputras (consist of Malays and indigenous people) followed by Chinese (23%), Indians (7%) and numerous other minorities (1%). These major ethnic groups are most likely to profess to either Islam, Christianity, Buddhism or Hinduism. In addition to all these heterogeneities, a vast repertoire of languages and dialects are spoken daily in Malaysia.

The pluralism of the Malaysian society would inevitably influence the healthcare practices in many instances from the development and implementation of policy (Enang & Ushie, 2012; World Health Organization, 2012), communication (Saha et al., 1999) and the general lifestyle (Zaini, 2000) of everyday Malaysian. Understanding this socio-cultural dimension would be critical to a successful healthcare delivery system. According to the World Bank, Malaysia is considered an upper-middle-income country and is predicted to be a high-income country by 2024 (The World Bank Group, 2019). As of 2019, the number of households living in extreme poverty is below 0.01% (Ministry of Finance Malaysia, 2019). Therefore, the government shifted its focus to the most deficient bottom 40% of the population who are more vulnerable to economic shocks from increasing cost of livings and financial burden from out-of-pocket payments for services like healthcare.

There are economic factors that also intertwine with the socio-cultural factors that influence the healthcare system. Tax and general revenue collected by the federal

government finance the public healthcare system. In contrast, patient's out-of-pocket payments or private health insurance finance the private healthcare sector. The mean household income varies between states, sex and ethnicity. The mean household income for Malaysia in 2016 was RM 6958 with the federal territories of Kuala Lumpur (RM 11,692) and Putrajaya (RM 11,555) with Selangor (RM 9463) scoring the highest mean household income in the country. While Perlis, Kedah and Kelantan were occupying the bottom three in the mean household income by the state at RM 4998, RM 4971 and RM 4214 respectively (Department of Statistics Malaysia, 2017).

Long-term healthcare finance and access issues are essential and need to be addressed due to Malaysia's increasing lifestyle-related disease prevalence. Malaysia's prevalence rate of type 2 diabetes is one of the highest in the Western Pacific region at 17.5%, and this estimate has doubled over the last two decades (Tee & Yap, 2017). Diabetic renal disease is the single most important cause of end-stage renal disease that requires renal replacement therapies at a very rapid rate. This cascading effect needs proactive healthcare policies that target issues at each level of the healthcare system, and the focus should shift from disease curation towards health promotion and disease prevention.

1.5 Research Question

ReTRAPP was designed to address the research question; what are the factors that influence the access to renal transplantation and post-transplantation outcome of adult renal transplant recipients (RTRs) in Malaysia?

The PICO framework was used as a process in evidence-based practice to aid in the development of the research question for ReTRAPP. It is mentioned that when the research question is divided into four components, it will facilitate the identification of relevant information about the topic of interest (Sackett, 1997). Table 1.1 illustrates how the PICO framework was adopted to formulate the research question as to the starting point for ReTRAPP.

Table 1.1: PICO framework to formulate the research question

Components	Variables
Population	Renal transplant recipients
Indicator	Socioeconomic status
Comparison	Renal transplant recipients of varying socioeconomic status
Outcome	Renal transplant access and outcome

The research questions underlying the investigation in this study are as follows

1. What is the general perception of key-informants on barriers and the solutions concerning the access to renal transplantation in Malaysia?
2. What is the association between the socioeconomic status of renal transplant recipients and the waiting time for renal transplantation in Malaysia?
3. What is the association between the socioeconomic status of renal transplant recipients and their post-transplantation survival in Malaysia?

4. What is the association between the socioeconomic status of renal transplant recipients and their post-transplantation quality of life?
5. What is the association between the socioeconomic status of renal transplant recipients and their financial burden from post-transplantation care?

1.5.1 Hypothesis

The hypothesis that is tested in ReTRAPP, based on the conceptual framework developed, is the association between socioeconomic factors on the access and outcome of renal transplantation in adults in Malaysia.

1.5.2 Aim

The primary aim of ReTRAPP is to study the factors influencing access to renal transplantation and the post-transplantation outcomes of adult RTRs in Malaysia.

1.5.3 Objectives

The following objectives are the core components of ReTRAPP to achieve the study aimed

1. To describe key-informants' perception of the barriers and solutions to access renal transplantation in Malaysia
2. To examine the impact of socioeconomic status on access to renal transplant (waiting time to transplantation)

3. To determine the association of socioeconomic status on the survival of the renal transplant recipient (survival time)
4. To evaluate the influence of socioeconomic status on quality of life among renal transplant recipients
5. To compare the financial burden (catastrophic health expenditure) of renal transplant recipients according to their socioeconomic status

1.6 Structure of the Thesis

This thesis is a compilation of six chapters. It comprises of a qualitative study, a quantitative study using secondary data and a quantitative study using primary data collection. This sequence corresponds to the objectives of ReTRAPP to aid the readers' understanding. The qualitative component explored the complex problem of renal transplantation in Malaysia and to explore solutions using the socio-ecological model framework. In contrast, the quantitative components aim to study the effect of socioeconomic status on the access to and outcome of renal transplantation in Malaysia.

Chapter two provides a review of relevant literature on renal transplantation practices globally as well as in Malaysia. It begins by highlighting the burden of chronic kidney disease and ESRD on the population as the main reason for renal replacement therapy. It continues with the discussion of health equity for renal transplantation. Subsequently, the practice and process of renal transplantation in Malaysia are comprehensively reviewed. To conclude the chapter, the key construct of the socio-ecological model as a conceptual framework in determining the access to renal transplantation was introduced together with the theoretical framework of ReTRAPP derived from the literature review.

The third chapter begins with the outline of the research methodology underpinning this study. The different methodological approach (qualitative and quantitative) in ReTRAPP are outlined separately for the readers understanding. This chapter highlights the different study design, ethical issues, data collection and analysis based on the different approaches in ReTRAPP. The context of ReTRAPP study describes the different population of interest as well as the different methods of recruitment for the study. The

chapter ends by discussing the safeguard of participants' personal information and general ethical considerations.

Chapter four organises the presentation of data analysis and the study findings for each of the different components of ReTRAPP. It begins with the thematic analysis of the qualitative data. The presentation of the qualitative findings is structured using the socio-ecological model on the barriers and solution to renal transplantation access in Malaysia. This segment would describe the individual, interpersonal, community, organisational and system-level factors. This chapter also presents relevant results for both quantitative studies. Results corresponding descriptive univariate and multivariable analysis are based on the relevant objectives.

The fifth chapter presents a summary of the study findings—a structured review of discussions presented according to the objectives of ReTRAPP. Next, the strengths and limitations of this study are categorised based on the different methodological approach of ReTRAPP.

The final chapter draws together the study findings from both the qualitative and quantitative approach and the theoretical framework outlined in ReTRAPP to present a brief conclusion of the study. It ends with implication for policy and practice, policy brief, suggestions for future research and concluding remark of ReTRAPP study.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter summarises the critical review of the literature with regards to chronic kidney disease (CKD) and renal replacement therapy (RRT). First, it provides an overview of end-stage renal disease (ESRD) and the modalities of RRT with the importance of renal transplantation. This is followed by a review of the associations between socioeconomic status and renal transplantation. A summary of the renal transplantation system in Malaysia is discussed with an overview of the legal framework and international policies that affect renal transplantation practices in Malaysia. This chapter concludes with the conceptual and theoretical framework for the study. Finally, it leads to the development of the research question.

2.2 Chronic Kidney Disease and End-Stage Renal Disease

Chronic kidney disease (CKD) and end-stage renal disease (ESRD) are a significant and growing problem globally and locally. CKD characterised by abnormal renal function or structure. The progression of CKD to ESRD typically occurs when the renal function deteriorates irreversibly. The prevalence of CKD is higher in older populations (Crowe et al., 2008). This progressive loss of function can be determined by measuring the serum creatinine level for glomerular filtration rate (GFR). Glomerular filtration is the process by which the kidneys filter the blood and removes excess body's wastes and fluids. GFR is a calculation that determines how well the kidneys filter the blood. It is one way of measuring renal function and categorising CKD, as illustrated in table 2.1.

Table 2.1: Stages of chronic kidney disease

GFR Stage	GFR (mL/min/1.73 m ^{2})	Description	Treatment stage
1	>90	Normal renal function but urine or other abnormalities point to renal disease	Observation, blood pressure control
2	60-89	Mildly reduced renal function, urine or other abnormalities point to renal disease	Estimate progression, blood pressure and risk factor control
3	30-59	Moderately reduced renal function	Blood pressure and risk factor control, evaluate and treat the complication
4	15-29	Severely reduced renal function	Planning for end-stage renal failure.
5	<15	Very severe, or end-stage renal failure	Renal replacement therapy (RRT)

Source: (Levey et al., 2003)
GFR – Glomerular Filtration Rate

2.3 Epidemiology of Chronic Kidney Disease and End-Stage Renal Disease

ESRD often is referred to as the last stage of CKD. It happens when there is a total or near-total loss of renal function, which requires renal replacement therapy (RRT). The global prevalence of CKD via a systematic review conducted by Hill, et al. estimates about 13.4% of the world's population is affected by CKD (N. R. Hill et al., 2016). Furthermore, the study substantiates other literature that finds women to be more prone to develop CKD than men.

In the Global Burden of Disease Study, CKD was at 12th place for global mortality with a considerable increase of 80% over the past 10 years that is second only to HIV/AIDS (Bikbov et al., 2020). Currently, there are over 2 million ESRD patients

globally (Saran et al., 2018) who require RRT to stay alive and this number is estimated to rise by 8% annually (Schieppati & Remuzzi, 2005). It also estimates that ESRD cases will increase disproportionately in low- and middle-income countries due to the rising elderly population and increased prevalence of both diabetes mellitus and hypertension (Liyanage et al., 2015; S. L. White et al., 2008).

Most of the data from other countries are derived from hospital-based data (Jha, 2009), unlike the national renal registry that is maintained by Malaysia. Hill et al. performed a systematic review and meta-analysis to determine the global prevalence of chronic kidney disease by pooling 6.9 million patients from 100 articles (N. R. Hill et al., 2016). The global prevalence of any renal damage (stage 1 – 5) was 13.4% (95% CI of 11.7–15.1%), and the prevalence of renal damage (stage 3 – 5) was at 10.6% (95% CI of 9.2–12.2%) (N. R. Hill et al., 2016). The breakdown of prevalence by stage is shown in table 2.2

Table 2.2: Global prevalence of chronic kidney disease by GFR staging

Stage	GFR (mL/min/1.73 m ^{2})	Prevalence (%)	95% CI
1	>90	3.5	2.8 – 4.2
2	60-89	3.9	2.7 – 5.3
3	30-59	7.6	6.4 – 8.9
4	15-29	0.4	0.3 – 0.5
5	<15	0.1	0.1 – 0.1

Source: (N. R. Hill et al., 2016)
GFR, Glomerular filtration rate; CI, Confidence interval

Most countries routinely collect information on the incidence and prevalence of renal replacement therapy, a proxy for the new and total cases of ESRD around the world. This is because most of these countries failed to recognise the diagnosis of ESRD or have restricted access to RRT. Bangladesh and Pakistan are countries with low ESRD rate

because of limited availability of RRT (Tsukamoto et al., 2010). The reported incidence and prevalence rate of ESRD in 2015 were markedly varied between the countries with Malaysia having one of the highest rates together with Taiwan, the Jalisco region of Mexico, Brunei, Thailand, Singapore and the United States (see figure 2.1).

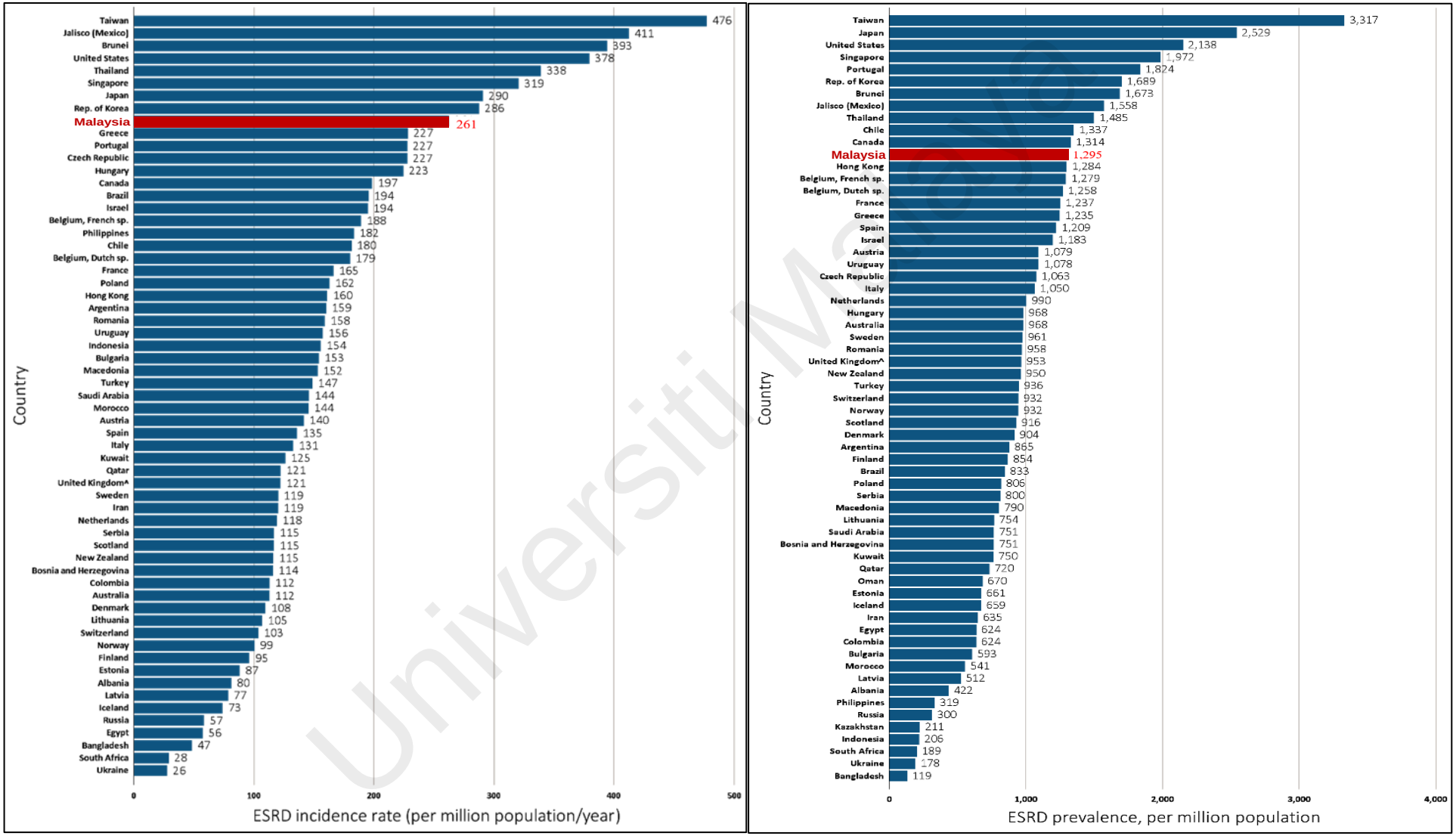


Figure 2.1: Incidence rate and prevalence rate of ESRD, by country, in 2015

Source: (Saran et al., 2018)

ESRD, End-Stage Renal Disease

Studies were conducted to examine awareness of diagnosis among people in economically developing countries, showed that fewer than 10% of patients with CKD knew of their condition (Ingsathit et al., 2010; L. Zhang et al., 2008). The numbers of CKD cases are higher than reported because the prevalence of diabetic kidney disease has increased by 39.5% from 2005 to 2015 globally (Wang et al., 2016). Figure 2.2 illustrates this rising trend of ESRD from 2002 – 2015 by country. It shows that the prevalence of the ESRD has risen sharply over last decade, driven by an increasing prevalence of diabetes (World Health Organization, 2016) and hypertension (Forouzanfar et al., 2017) in the population (Mills et al., 2015). From the figure, Malaysia was the top 5 country on the list with an increase of 154% in ESRD prevalence from 2002 – 2015.

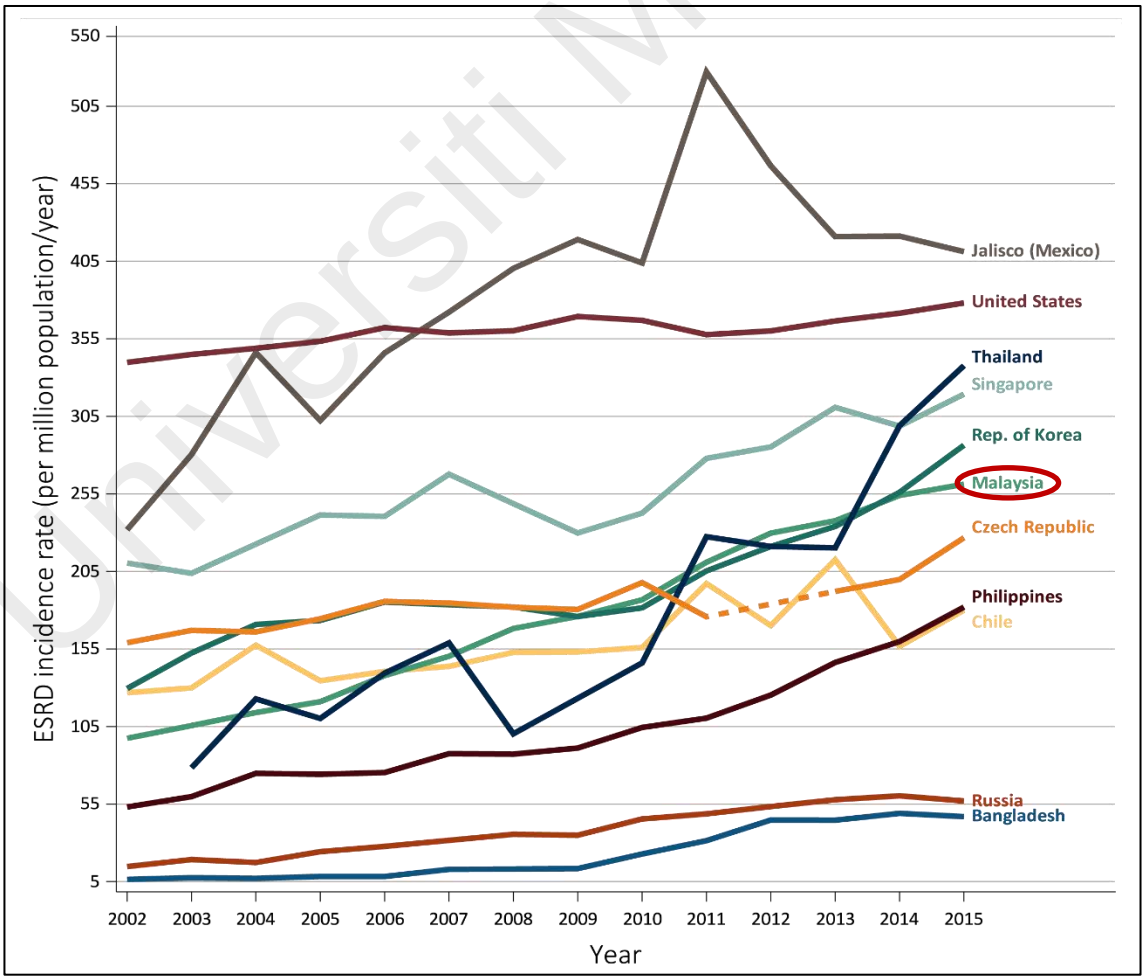


Figure 2.2: Trends in the ESRD incidence, per million population, by country, 2002 – 2015

Source: (Saran et al., 2018)

ESRD, End-Stage Renal Disease

In Malaysia, data on the epidemiology of ESRD are made available through the Malaysian Dialysis and Transplant Registry (MDTR) Report and updated annually. From this annual report, the prevalence and incidence of ESRD patients are growing at a linear rate. Figure 2.3 shows the linear growth of ESRD patients requiring dialysis from 2007 – 2016.

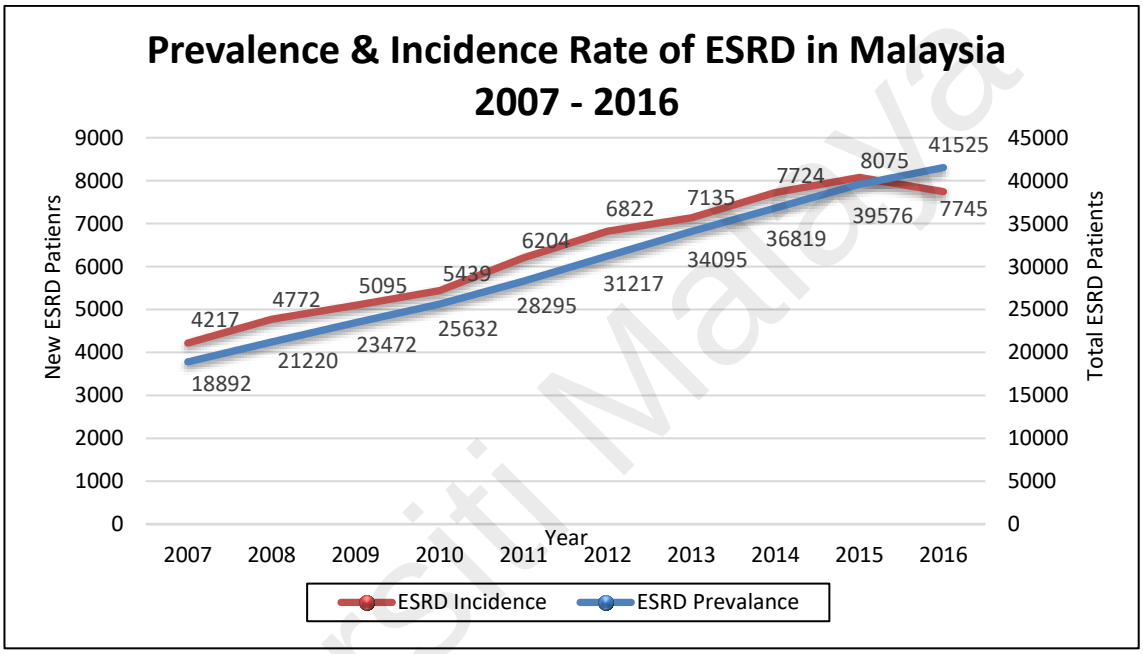


Figure 2.3: Prevalence and incidence rate of ESRD in Malaysia, 2007 – 2016
Source: (H. S. Wong & Goh, 2018)
ESRD, End-Stage Renal Disease

The common causes of ESRD in adults in Malaysia as indicated by MDTR are

1. Glomerulonephritis
2. Diabetes mellitus
3. Hypertension
4. Obstructive uropathy
5. Drug or toxic nephropathy
6. Autosomal dominant polycystic kidney disease
7. Hereditary nephritis
8. Others

9. Unknown cause (H. S. Wong & Goh, 2018)

The number of ESRD cases is estimated to increase from 51,269 and 106,249 between 2020 and 2040, respectively (Bujang et al., 2016). The approximate doubling of cases may be attributed to an increase in population size, an ageing population, and the increase of non-communicable diseases such as diabetes mellitus and hypertension. More than 75% of ESRD causes in Malaysia are attributable to these risk factors (H. S. Wong & Goh, 2018).

Among adults, the primary cause of ESRD was mainly diabetes (65%) and accounted for more than half of all new dialysed patients in the last decade, followed by hypertension (19%) (H. S. Wong & Goh, 2018). It was corroborated the findings from other high income and low- and middle-income countries (Jha et al., 2013). Table 2.3 tabulates the primary causes of ESRD for 2016 in Malaysia. The exponential rise in diabetic renal disease underpinned with an inadequate healthy lifestyle has driven the population to be overweight and obese. It had led to an increase in the ESRD burden globally and especially for Malaysia.

Table 2.3: Primary renal disease causing ESRD in Malaysia, 2016

Disease	Frequency of cases	Percentage
Diabetes mellitus	4980	65
Hypertension	1456	19
Unknown cause	843	11
GN / SLE	230	3
Obstructive nephropathy	77	1
Toxic nephropathy	77	1
ADPKD	0	0
Others	0	0

Source: (H. S. Wong & Goh, 2018)
ADPKD, Autosomal dominant polycystic kidney disease
GN, Glomerulonephritis
SLE, systemic lupus erythematosus

Despite the advancement in the treatment of ESRD, the morbidity and mortality rates for this population remains high. The USRDS reported that only 51% of dialysis patients, and 82% of those who received renal transplants, are still alive three years after the start of ESRD therapy (Bethesda, 2012). The poor prognosis is associated with the patient's increased age as well as co-morbid conditions that worsen the health status. Comorbidities like diabetes mellitus and cardiovascular disease with ESRD will increase the patient's risk of death (Saran et al., 2018).

2.4 Renal Replacement Therapy

Before the 1960s, treatment option for ESRD patients were relatively limited. Dialysis clinics were a new development, and renal transplantation was in its early stages of research. Renal Replacement Therapy (RRT) is required when renal function is below 15%. RRT replaces the normal blood-filtering function of the kidneys either by dialysis (Haemodialysis or Peritoneal-dialysis) or renal transplantation.

The demand for RRT is increasing nationally and globally due to the increase in chronic conditions (especially Type 2 diabetes), ageing populations, and increased survival rates of people with CKD and ESRD (Garcia et al., 2012). Haemodialysis or peritoneal-dialysis are the most common therapies used to manage uraemia associated with ESRD, and both produce similar patients' survival rate (Pannu et al., 2008).

Haemodialysis (HD) is a treatment for renal failure by filtering the blood by through a machine, which is done three times a week for 4 hours at a dialysis centre. HD can replace part of the renal function, but it is not a cure for renal failure (National Institute of Diabetes and Digestive and Kidney Diseases, 2016). In 2016, HD remained the most

common treatment modality for ESRD patients in Malaysia, with approximately 35,740 (86%) out of a total of 41,525 ESRD patients are undergoing HD (H. S. Wong & Goh, 2018). Figure 2.4 shows Malaysia's preference for HD as the most common RRT option, which is like most of the other low and middle-income countries.

Peritoneal-dialysis (PD) is a therapy typically managed by ESRD patients at home. PD uses a surgically-placed catheter inside the peritoneum of the abdomen. It filters the blood inside the body by using a dialysate. It usually takes about 30-40 minutes to complete one cycle of fluid change and needs to be replaced four times a day. PD may be more efficient in maintaining lower serum levels of urea nitrogen and creatinine while improving the haemoglobin and blood pressure control (Menon et al., 2001). PD is also associated with severe complications such as peritoneal sclerosis (Moinuddin et al., 2014) and bacterial peritonitis (L. Williams et al., 2015) which could be fatal.

Figure 2.4: Renal replacement therapy modalities (either transplantation or dialysis) for patients with end-stage renal disease, by country, in 2013
Source: (Robinson et al., 2016)

Among the RRT, renal transplantation is the preferred choice because it is associated with better quality of life (WHOQOL Group, 1995), survival (M Tonelli et al., 2011) and more cost-effective (Eriksson et al., 2016) as well. However, in Malaysia, the limited availability of organs for transplantation has made dialysis the more common renal replacement modality (H. Wong & Goh, 2015). The prevalence of dialysis has also been increasing between 2006 and 2015, as illustrated in Figure 2.5. The proportion of renal transplantation is higher for high-income countries. For example, the USA has 30% of ESRD patients living with a renal transplant (Saran, Li, et al., 2017) while other high-income countries like France, UK, Norway, and Sweden have a higher rate of RTR between 40% and 50% (Pippias et al., 2015).

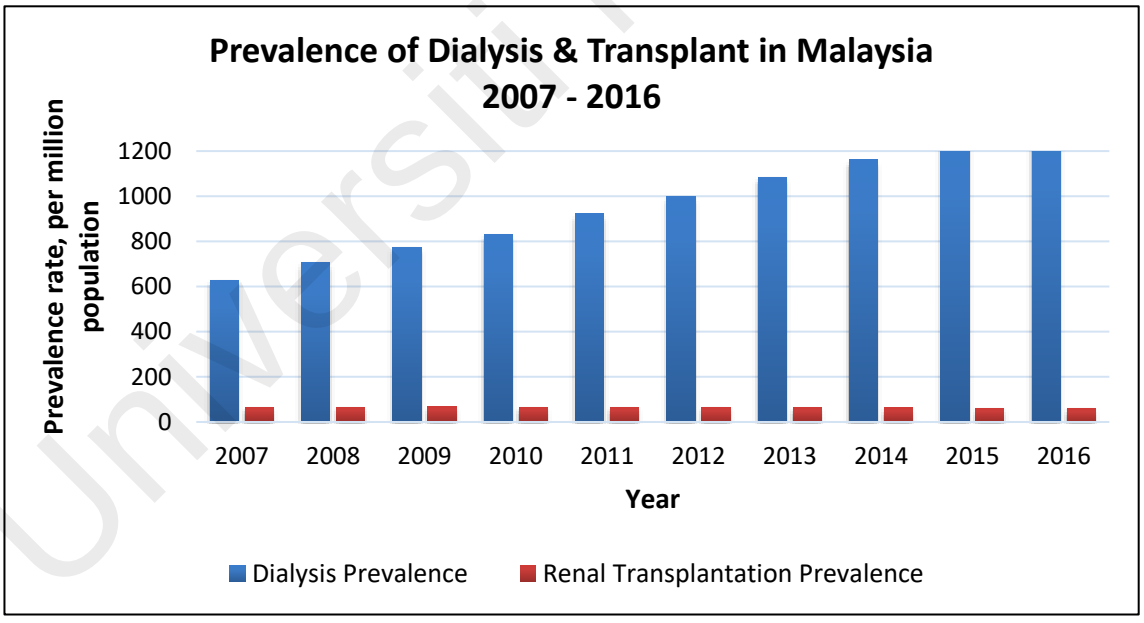


Figure 2.5: Prevalence of Dialysis & Transplant in Malaysia 2007 – 2016
Source: (H. S. Wong & Goh, 2018)

2.5 Historical Overview of Renal Transplantation Globally and Locally

The first successful renal transplantation was performed in 1954 by Dr Joseph Murray at the Peter Bent Brigham Hospital in Boston (Starzl, 2000). This transplantation was successful when compared to many previous transplantations. It was conducted between identical twins, and the recipient's body did not reject the kidney (Starzl, 2000). He later performed the first successful renal transplantation from a deceased donor in 1962 at the same hospital. Dr Murray later received a Nobel Prize for Physiology / Medicine in 1990 for his contribution and pioneering work in transplantation (Papalois & Najarian, 2001).

In Malaysia, the first organ transplantation was a living-donor renal transplant performed on December 1975 at Hospital Kuala Lumpur. The recipient received a kidney from his brother and survived for 30 years before succumbing to significant infection. It was followed a year later by the first deceased donor renal transplant (Ministry of Health Malaysia, 2007). There were a total of 669 renal transplantation performed in Malaysia reported to MDTR between 2005-2014 (H. Wong & Goh, 2015). Figure 2.16 illustrates the significant renal transplantation milestones in Malaysia.

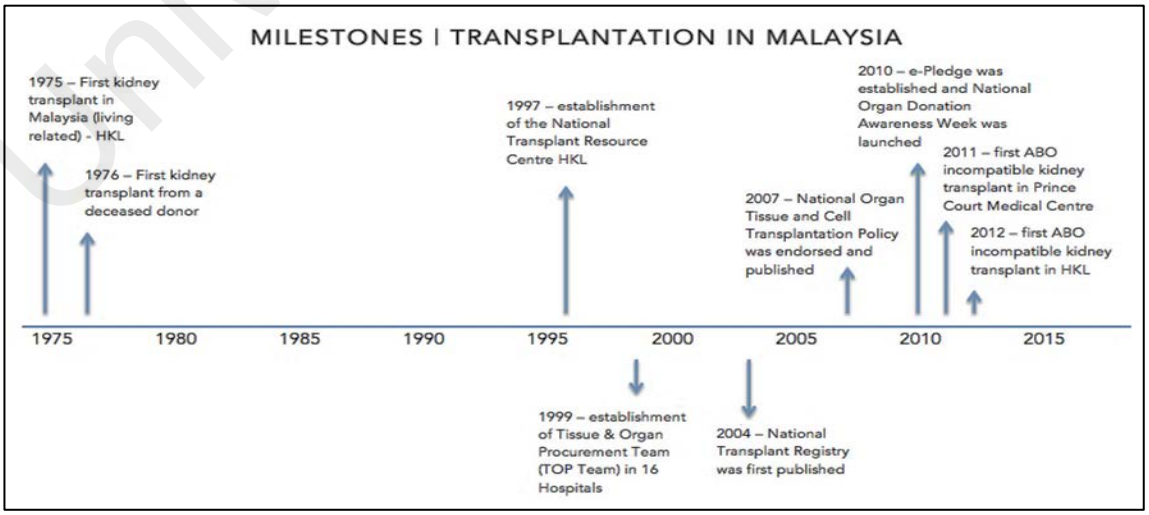


Figure 2.6: Renal transplantation milestones in Malaysia
Source: Transplantation Unit, Medical Development Division, MOH 2016

2.6 Renal Transplantation

Renal transplantation is the preferred choice for a minority of ESRD patients with ESRD. Renal transplantation is a surgical procedure that transplants a healthy donor kidney into the recipient's body. There are two types of kidney donors for transplantation

1. Living donor
    - A kidney is removed from a healthy donor and surgically placed in ESRD patient
    - Advantages of living donor renal transplantation to the recipient (Weitz et al., 2006)
        a) Shorter waiting time
        b) Living renal transplantation is an elective surgery – well planned and performed
        c) Kidneys from living donors work better and longer compared to deceased kidney (better quality of life and survival outcome)
    - Kidney donor must be in excellent health, well informed about transplantation, and able to give informed consent
    - There is a minimal risk of death for the kidney donor, i.e. 3.1 death in every 10,000 donations (Ministry of Health Malaysia, 2011e) which has a similar risk of performing appendicectomy
2. Deceased donor
    - Deceased kidney donor comes from individuals who suffered brain death
    - Kidney harvested from individual who has pledged to donate their organs for transplantation at the time of death or with consent from families to donate organs
    - After consent for donation obtained, the kidneys are removed and stored until a recipient selected

A patient undergoing a renal transplant most often will receive one kidney. The surgeons generally would transplant the kidney in the lower abdomen, near the groin. Unless the damaged kidneys cause infections or high blood pressure or are cancerous, they will remain in the body. Figure 2.7 illustrates the renal transplant surgery.

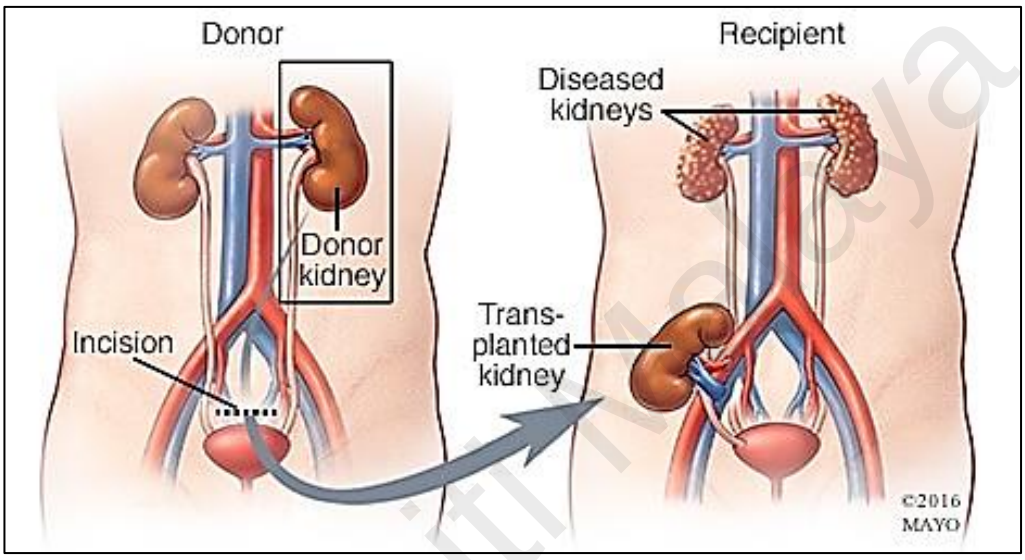


Figure 2.7: Renal Transplant surgery showing anastomosis of blood vessels and ureter with native kidneys in left in place
Source: (Mayo Clinic, 2018)

2.7 Association of Socioeconomic Status on Renal Transplantation

Socioeconomic status (SES) is widely measured using levels of education, employment status and income (Adler et al., 1994). SES is related to health in a few ways, particularly the

1. environments that patients exposed to which impact their health
2. health-promoting or negating behaviours that people are engaged in
3. utilisation of health care services (Adler & Newman, 2002)

The concept of ESRD patient's SES is an essential consideration in the renal transplantation in Malaysia. Marmot states that SES, as a social determinant of health, has a significant influence on health in terms of better health behaviours and outcomes (Marmot, 2005). Many works of literature that have established an undisputable positive association between SES and health status and a negative association with mortality at an individual level (Lynch et al., 2004). Specifically, some have demonstrated that SES affects care throughout the transplant process from access (Bendorf et al., 2013) and the outcome (Gordon et al., 2010) of renal transplantation. SES can have an indirect impact on the need or health status ESRD patients such as:

1. recognition and response to symptoms of ESRD
2. knowledge of ESRD
3. motivation to get well
4. access or choice of health services (dialysis or renal transplantation)

It is well known to the healthcare professional that patients with lower SES have a much worse health outcome (Pickett & Pearl, 2001). While patients' socioeconomic status is the most significant social influence on health and wellbeing, income distribution in the community as a subset of SES also plays an important part. ESRD patients' income influences their daily living because it relates material deprivation with the social opportunity that would inadvertently exert control over the patients' lives. Patients with lower incomes, often lack resources and access to nutritious food, adequate housing and safe working conditions which can impact negatively on their health (Marmot & Commission on Social Determinants of Health, 2007). This statement is congruent with multiple studies conducted that identified associations between low income and adverse medical outcomes, such as higher all-cause, cardiovascular, cancer mortality (J. M. Major

et al., 2010) and even more so for ESRD and renal transplantation (Kalil et al., 1992; Woodward et al., 2008).

Research consistently reports that education is associated with improvement in the health of the population. In the context of ESRD patients, higher educational attainment is associated with more significant opportunity to be wait-listed and to receive a kidney (Goldfarb‐Rumyantzev et al., 2012; Schaeffner et al., 2008) compared to the patient's with lower educational attainment that is more prone for graft failure (Francis et al., 2016; Mistretta et al., 2009). Educational attainment correlates with employment status because those with higher educational attainment are more likely to be employed. ESRD patients with tertiary education with stable employment have a better opportunity to be wait-listed for renal transplantation (Neri et al., 2013). ESRD patients in the USA with higher education have a greater chance of being wait-listed, receiving a kidney and are less likely to have allograft loss compared to ESRD patients with lower education (Schaeffner et al., 2008). It suggests that the communication barriers between healthcare professionals and ESRD patients may be mitigated and minimised in patients who are better-educated.

As the duration of dialysis (especially HD) increases, the rate of employment dramatically reduces and may never recover even after transplantation. However, patients who were working before renal transplantation were more likely to be employed post-transplantation (Eppenberger et al., 2015; Hathaway et al., 2003; J. Kim et al., 2017). Research has demonstrated that employment status in the post-transplantation period was strongly and independently associated with a lower risk for graft failure and RTRs mortality at 1-year post-transplantation (Petersen et al., 2008) as well as better health-related quality of life (Ortiz et al., 2014). Besides, employment has a positive impact on the reestablishment of the RTRs' identity, self-esteem and quality of life post-transplantation (Callahan, 2005).

In essence, SES has a strong influence on many aspects of the healthcare system as well as the access to essential and speciality healthcare services, compliance to medication and outcome after surgical procedures (Axelrod et al., 2010). Studies have shown that higher SES increases the access to renal transplantation and improves the outcome for patients with ESRD (Francis et al., 2016; Schold et al., 2013). Besides that, a higher SES may result in early nephrology referral, higher rates of pre-emptive transplantation, shortened duration of dialysis, and improved outcomes of renal transplantation (Axelrod et al., 2010). The World Health Organization (WHO) Commission on Social Determinant of Health acknowledged that this avoidable disparity in health between groups of people are determined by the social and economic gradient in which they are living. The lower the SES, the weaker the health (WHO Commission on Social Determinants of Health & World Health Organization, 2008).

2.8 Socioeconomic Status and Access to Renal Transplantation

Renal transplantation is the preferred treatment of choice for ESRD is a fact that is substantiated by research. However, the current demand for renal transplantation is higher than the supply (H. S. Wong & Goh, 2018). Despite a regulated system for organ allocation in Malaysia (H. S. Wong, 1999), disparities may exist in various stages of the renal transplantation process. The process includes referral, evaluation, waitlisting and organ receipt as documented by studies in high-income countries (Axelrod et al., 2010; Couchoud et al., 2012; Goldfarb‐Rumyantzev et al., 2012; Mathur et al., 2010). Even though SES seems to play an intricate role in the transplantation services because SES affects the care throughout the whole transplantation process, SES is relevant and should be a significant consideration in determining access to renal transplantation (Kihal-Talantikite et al., 2016).

Most studies examining SES determinants to access to deceased donor renal transplantation focused on racial disparities (Kasiske et al., 1998). The effect of poverty on these disparities is conducted in high-income countries. However, few had examined the population in low- and middle-income countries. In these studies, socioeconomic inequalities in accessing renal transplantation have been highlighted in the United States of America (USA) (Axelrod et al., 2010; Stolzmann et al., 2007), United Kingdom (UK) (Udayaraj et al., 2010), Australia and New Zealand (Grace et al., 2013). These studies indicated a role for various non-medical factors, such as health income status (J. Gill et al., 2013), employment status (Goldfarb‐Rumyantzev et al., 2011)and educational attainment(Axelrod et al., 2010; Schaeffner et al., 2008) which are SES indicators of interest in ReTRAPP.

Morton et al. conducted a metanalysis that demonstrated a strong association between disadvantaged ESRD patients with inadequate access to quality treatment, which includes renal transplantation (R. L. Morton et al., 2015). Most studies conducted on education have indicated that ESRD patients with higher educational attainment were associated with a higher chance of accessing renal transplantation (Goldfarb‐Rumyantzev et al., 2012; Khattak et al., 2010; Schaeffner et al., 2008). Household income is an essential socioeconomic determinant of health as individuals with higher household income have greater access to living organ donors (J. Gill et al., 2013).

2.9 Socioeconomic Status and Outcome of Renal Transplantation

2.9.1 Survival Rate of Renal Transplant Recipients

The discovery of immunosuppressive drugs in the late 1970s and progress in surgical techniques were a turning point for successful organ transplants. It has led to better graft and patient survival after renal transplantation over the past decades. Data from the National Renal Registry demonstrate a 5-year survival for both renal transplantation at 95% compared with 89% from a decade before (Yahya et al., 2014). Figure 2.8 shows the overall patient survival trend after renal transplantation from 2007 – 2016 in Malaysia.

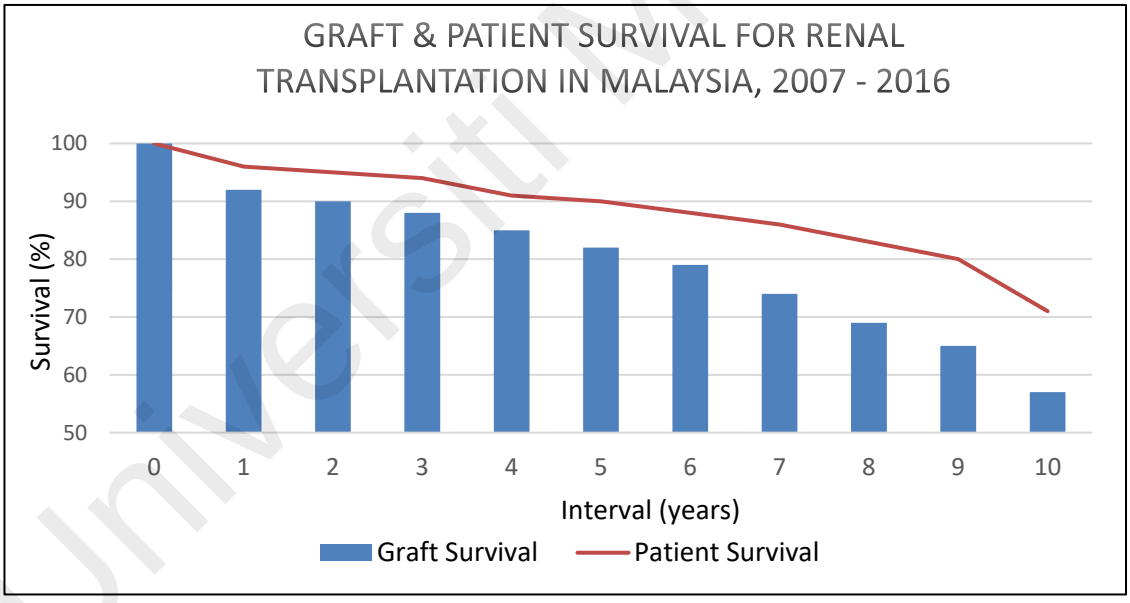


Figure 2.8: Unadjusted graft and patient survival for Malaysia, 2007 – 2016
Source: (H. S. Wong & Goh, 2018)

The USA Renal Data System showed that ESRD patients undergoing renal transplantation are predicted to live 17 years longer than if they remain on dialysis (Bethesda, 2005; Wolfe et al., 1999). The MDTR data from Malaysia demonstrates similar finding of 5-year and 10-year overall graft and patient survival when compared to other countries in the region; namely Singapore and Brunei (Tan et al., 2014) and USA

(Saran, Robinson, et al., 2017). A summary to compare unadjusted 1-year and 5-year survival of living and deceased renal transplantation between Malaysia and other countries are as tabulated in Table 2.4.

Table 2.4: International comparison of living and deceased renal transplantation for unadjusted patient survival

Country	Source	Patient Survival (%)			
		Living Transplant		Deceased Transplant	
		1-year	5-year	1-year	5-year
Malaysia	**(H. S. Wong & Goh, 2018)**	**99**	**98**	**92**	**88**
Singapore	(National Registry of Diseases Office, 2018)	99.1	96.7	97.3	91.2
Thailand	(Thai Transplantation Society, 2015)	98.8	96.5	96.3	91.4
United States of America	(Saran, Robinson, et al., 2017)	98.6	92.7	95.6	83.5
United Kingdom	(NHS Blood and Transplant, 2017)	99	94	97	88
Australia	(ANZDATA Registry, 2017)	99	96	97	90
New Zealand	(ANZDATA Registry, 2017)	97	90	98	88

With the rapid advancement in healthcare over the past few decades, clinical care for ESRD patients has drastically improved as demonstrated by (Meier-Kriesche et al., 2001) research that showed a reduction in mortality rates for both RTRs and ESRD on dialysis. However, it is essential to note that renal transplantation still achieved a better

long-term survival over patients with ESRD who receive treatment with dialysis (Sahar Bayat et al., 2009; Jain et al., 2009). Figure 2.9 illustrates a similar pattern in Malaysia with higher survival rates of transplanted patients compared to patients on dialysis (H. S. Wong & Goh, 2018).

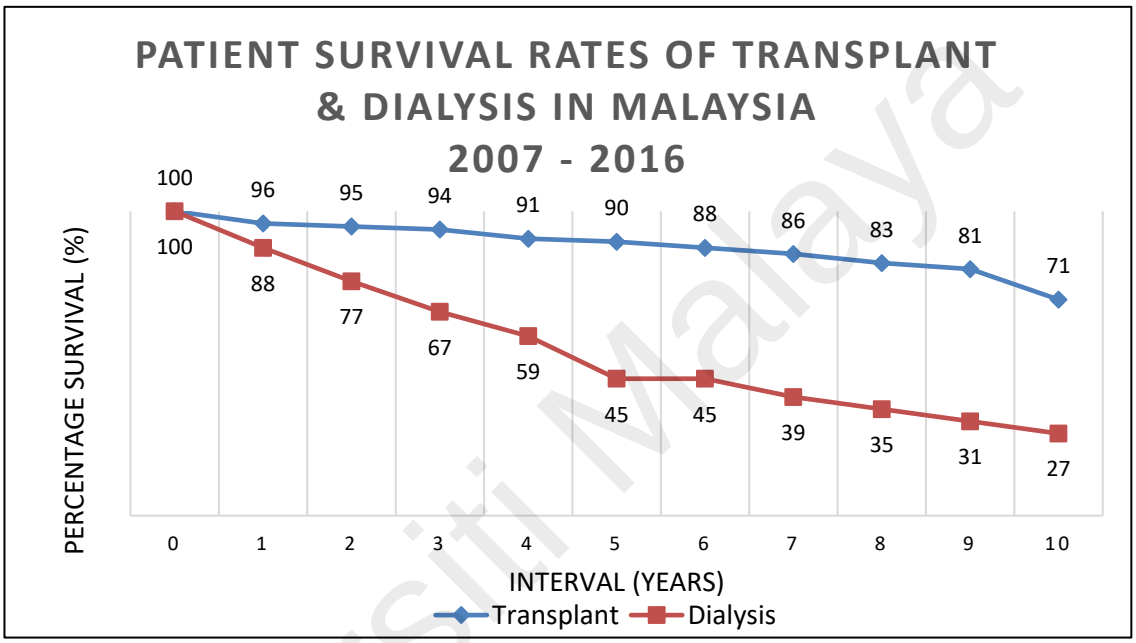


Figure 2.9: Unadjusted patient survival rates of dialysis vs transplant in Malaysia
Source: (H. S. Wong & Goh, 2018)

SES is known to affect healthcare outcome. The indicators of SES, such as low educational attainment, low household income, and unemployment, are determinants that adversely affect health (Goldfarb-Rumyantzev et al., 2006). Goldfarb postulated that RTRs with higher educational attainment would earn better income that would translate to better able to pay for medication leading to better survival (Goldfarb-Rumyantzev et al., 2006). It was further substantiated by Axelrod et al., who demonstrated that RTRs patients with higher SES are strongly associated with better outcomes which include reduced risk of subsequent patient death (Axelrod et al., 2010). It was suggested that RTRs SES might be an essential factor in the compliance to medication and follow up

because patients with lower SES may not be able to understand the importance of compliance which may lead to reduced survival rate (Denhaerynck et al., 2005).

2.9.2 Quality of Life of Renal Transplant Recipients

Renal transplantation studies have established that ESRD patients notice improvements in their global quality of life (WHOQOL Group, 1995), especially physical function (Kostro et al., 2016; H. Lim et al., 2016; Maglakelidze et al., 2011). A systematic review conducted by Tonelli summarized that patients favoured renal transplantation over dialysis (M Tonelli et al., 2011). Many studies suggest that after transplantation, RTRs recover some capacities that they possessed before the ESRD because the transplant allows a less restrictive diet (Nagaoka et al., 2016). They were also more satisfied with their health, more involved in social activities, and were more mobile after renal transplantation compared to when they were on HD (Raymond et al., 2016). Younger RTRs were noted to be more adaptive to the working and living environment after renal transplantation (Aasebø et al., 2009). Figure 2.10 illustrates the mean QOL findings based on the SF-36 questionnaire for renal transplantation which fairs much better than dialysis.

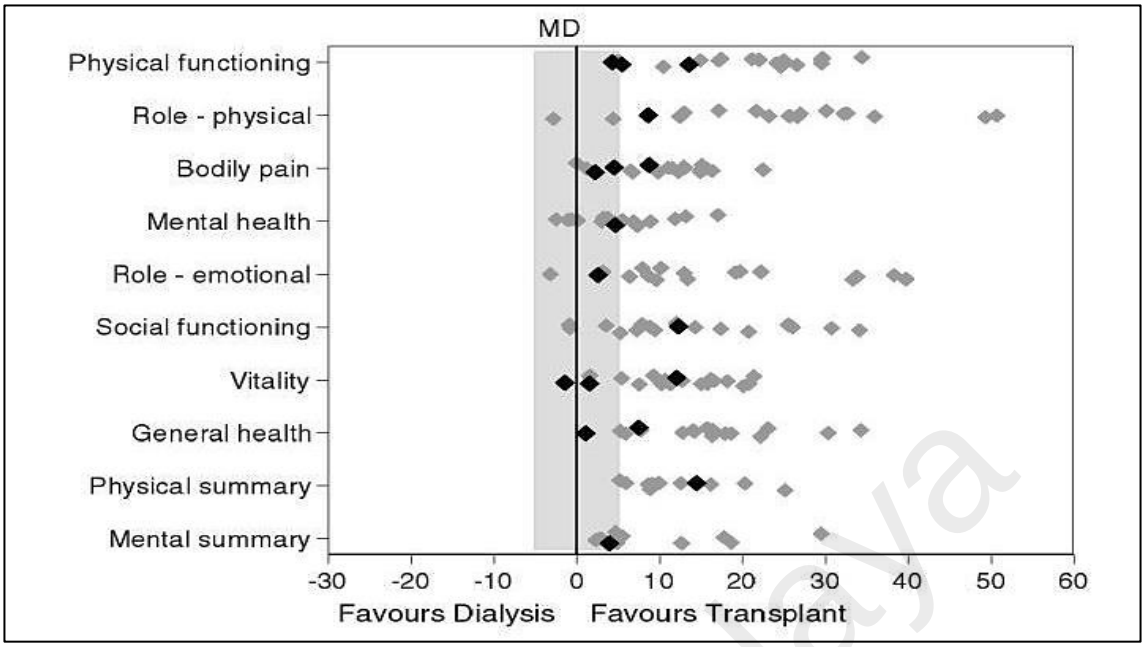


Figure 2.10: Mean differences (MD) in the domain of SF-36 questionnaire comparing transplant and dialysis
Source: (M Tonelli et al., 2011)

Legend

- small solid grey diamonds (♦) represent the mean difference in SF-36 domains between transplant patients and either HD or PD patients (for each study); are unadjusted mean differences
- The small solid black-coloured diamonds (♦) are adjusted mean differences
- The shaded grey region denotes the minimal clinically significant difference for SF-36 domains
- MD is mean difference

Another generic tool that was used by researchers from Brazil (Mendonça et al., 2015), Thailand (Junchotikul et al., 2015) and Poland (Tomasz & Piotr, 2003) was the WHOQOL BREF questionnaire. It produced findings that were congruent with the findings concerning QOL measured with the SF-36 questionnaire, which were the improvement in QOL, especially in the physical aspects of the RTRs. Even though many kinds of research have been conducted to compare the QOL of renal transplantation and ESRD patients on dialysis, but few studies were done to compare QOL between RTRs;

1. QOL at below one year and more than one year which has no significant difference (Kong & Molassiotis, 1999)
2. QOL comparing between living-donor and deceased renal transplants by (Suzuki et al., 2012) showed that living-donor RTRS have an improved QOL

Following the literature review, it was interesting to note that many kinds of research were conducted to examine the QOL of renal transplant donors too. It is in response to the promotion of living-donor transplantation by clinicians because it produces better outcomes for RTRs when compared to deceased renal transplant. These researches revealed that the QOL of kidney donors remained constant and were unaffected by the renal transplantation (Giessing et al., 2004; Hossain et al., 2015; Lumsdaine et al., 2005). Even though many hypothesized that there would be a reduction in QOL during the first year post-surgery, but it was disproved by (Klop et al., 2018) as it showed an insignificant difference.

2.9.3 Financial Burden for Renal Transplant Recipients

Dialysis, as an RRT treatment modality creates a tremendous financial and societal cost to the healthcare provider and the ESRD patients (Mushi et al., 2015). It was substantiated by a systematic review by Jarl and Gerdtham that supports renal transplantation, and the subsequent medical follow-up is more cost-effective compared to dialysis (Jarl & Gerdtham, 2011). Although research showed a higher cost for renal transplantation initially, the cost of maintenance for RTRs is lower compared to other RRT modalities like haemodialysis (Haller et al., 2011; Jensen et al., 2014; Loubeau et al., 2001; Rosselli et al., 2015; Sánchez-Escuredo et al., 2015).

RRTs are amongst the most commonly studied treatments modalities in health economics, and renal transplantation is proven to be much more cost-effective than HD (Eriksson et al., 2016; Haller et al., 2011; Huang et al., 2008; Rosselli et al., 2015). A 4-year study conducted in Saudi Arabia (Al-Jedai et al., 2012) showed that the cost of renal transplantation is aggregated at the first year post-transplantation with 85% of the total expenditure which will subsequently reduce to 6.75% for the second year, 2.6% for the third year and finally 2.1% for the fourth year. However, the cost of haemodialysis for the four years was constant. It leads to a linear accumulative increase to the healthcare cost, as shown in Figure 2.11. The average 4-year actual total cost per patient was US $210,779 and the US $317,186 for RTRs and patients who are on haemodialysis respectively. It shows the cumulative cost of haemodialysis surpassing the costs associated with renal transplantation at 31 months. The predicted savings in cost for renal transplantation after 31 months is $33,943 annually.

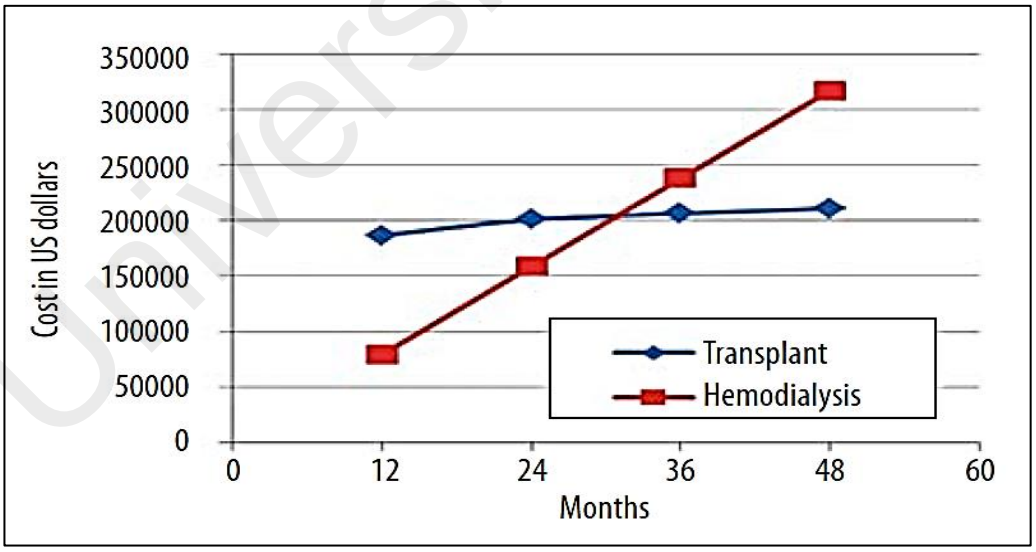


Figure 2.11: Cumulative cost between transplant and haemodialysis over four years in Saudi Arabia
Source: (Al-Jedai et al., 2012)

Renal transplantation is generally cost-effective compared to dialysis (mainly HD). In 2009, the National Health Service (NHS Blood and Transplant) of the U.K. spent £30,800 per patient per year on HD while the cost of renal transplantation is £17,000 per patient per transplant with the addition of £5,000 per patient per year for immune-suppressive medication. These functioning transplants are currently saving the NHS £50.3 million in dialysis costs each year (National Institute for Health Excellence, 2011).

According to Hooi et al., the expenditure by the Ministry of Health (MOH) for each ESRD patient on dialysis is at RM38,138 per year (Hooi, Lim, et al., 2005) – adjusted to 2009 (Bavanandan et al., 2015). Renal transplantation incurs a discounted cost per life-year of RM29,482 for living-donor renal transplant and RM45,234 for deceased donor renal transplant for MOH (Bavanandan et al., 2015). However, these figures are preliminary, and no cost-effective analysis was conducted to compare dialysis and renal transplantation. Based on the literature reviewed, there are currently no figures on the comparison of cost between the different modalities of RRT since Lim et al. and the study only explored the cost between HD and PD without considering the cost of renal transplantation (T. Lim et al., 1999). To the knowledge of the Researcher, studies conducted on the financial burden of renal transplantation are limited to the healthcare system rather than on renal transplant recipients (Bavanandan et al., 2015; Eriksson et al., 2016; Salamzadeh et al., 2014). With better and more effective drugs for renal transplantation that are excluded from the government's formulary or blacklisted patients for subsidized medication because of transplant tourism, the out-of-pocket payments of the medication by renal transplant recipients may increase causing catastrophic health expenditure.

2.10 Health Equity for Renal Transplantation

WHO states that universal health coverage (UHC) aims for everyone to have access to promotive, preventive, curative, rehabilitative and palliative health services. Furthermore, the services must be of sufficient quality to be effective and ensure that the people using these services are protected against financial hardship (Evans & Etienne, 2010). The healthcare system should be capable, efficient, and well-managed to meet the health needs of the community through people-centred care to achieve UHC. WHO details critical criteria for UHC which includes

1. Affordable healthcare system to avoid financial risk when using the service
2. Available essential medicines and technologies to diagnose and treat medical problems
3. Well-trained, motivated health workers to provide the services to meet patients' needs based on the best available evidence
4. Address social determinants of health such as education, living conditions and household income that affect access to health (Evans & Etienne, 2010)

Because ESRD is a life-threatening condition, RRT is required to sustain the lives of ESRD patients. Therefore, ESRD services are considered essential care under UHC. This assertion is practised in the USA by the adoption of ESRD services in the Affordable Care Act of 2010 (Watnick et al., 2012). Its goals are in line with UHC to deliver higher-quality care at lower costs by increased sharing of financial risk.

By 2020, the annual incidence of ESRD will be 10,208 patients and the prevalence will be 51,269, with a 1.5-fold increase in the overall number of patients on dialysis (Bujang et al., 2016). Because of the rapid increase in ESRD cases, the demands for dialysis and renal transplantation have also surge linearly. With the improvement in

immunosuppressive drug therapy and surgical methods, the success rate of renal transplantation has improved drastically, making it the preferred choice of ESRD care. However, the concerns for the availability of kidneys for transplantation comes into question.

Attention should not be focused just on renal replacement therapy when dealing with the issue of rising ESRD cases in Malaysia. Figure 2.12 shows a similar strategy that is being practised in New Zealand to deal with ESRD that is also exercised in Malaysia. The UHC approach should be adopted to deal with the burden of non-communicable diseases by

1. promoting a healthy lifestyle and increasing awareness
2. preventing the worsening of undetected disease by screening
3. controlling the disease from developing complications

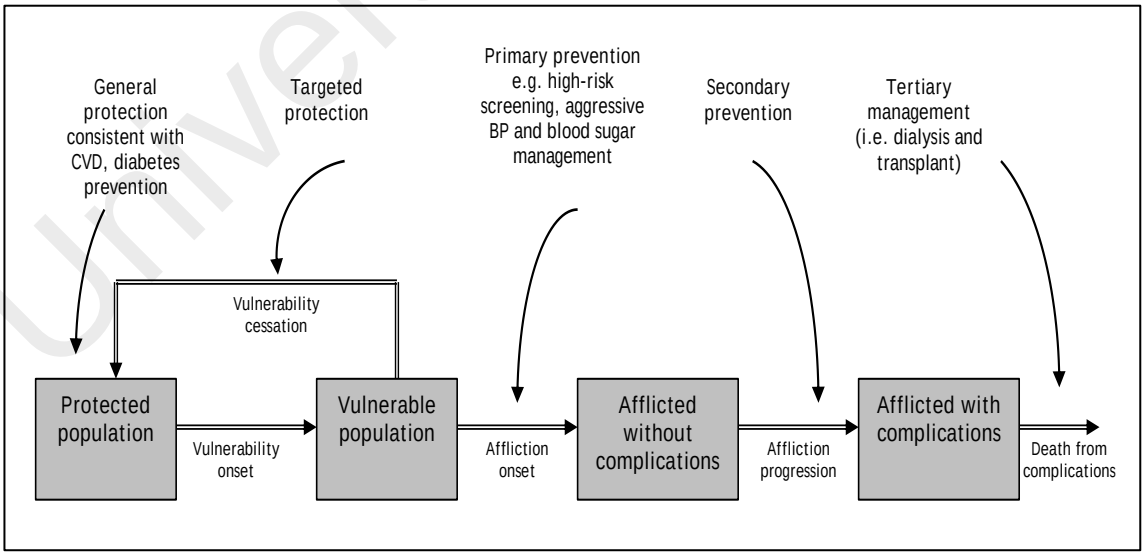


Figure 2.12: Strategic framework for the prevention and management of ESRD patients
Source: (National Renal Advisory Board, 2006)

The second component of UHC is to ensure that ESRD patients are not exposed to financial hardship due to renal transplantation. Research in India documented financial hardship acquired by ESRD patients undergoing transplantation in a public hospital was due to out of pocket payment for the direct and indirect expenses due to renal transplantation (Ramachandran & Jha, 2013).

For UCH to be successful, healthcare financing is essential with the emphasis of reducing out-of-pocket (OOP) payments. WHO defines OOP payments as direct payments made by individuals to healthcare providers at the time of service used which excludes any prepayment for health services, e.g. taxes or specific insurance premiums or contributions and reimbursements to the individual who made the payments (World Health Organization, 2013). Apart from OOP, healthcare financing can also be supported by the government through taxation, social insurance through payroll, taxes or direct contributions and private medical insurance. Figure 2.13 shows the different healthcare financing methods that are available in Malaysia.

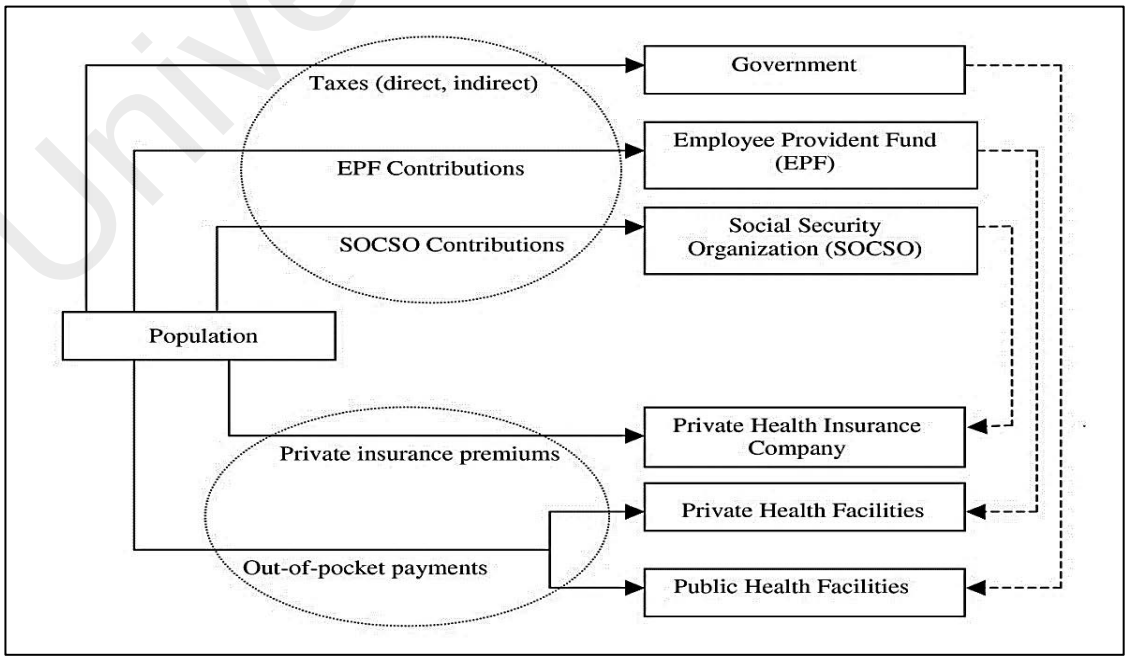


Figure 2.13: Types of healthcare financing in Malaysia
Source: (Yu et al., 2008)

Under UHC, the most vulnerable population should have access to health services they need without financial restrictions. By establishing prepayment and consolidating the resources for the healthcare system, these vulnerable population would be safeguarded from financial burden for essential healthcare services. The use of OOP payment to finance healthcare systems do have its limitations, but among the most apparent would be that it discourages people from seeking care. It is more evident for populations who are socioeconomically disadvantaged and are more likely to prioritize payment for food and housing rather than healthcare (Australian Bureau of Statistics, 2017; Buzuzi et al., 2016; Rahman et al., 2013; Srivastava & McGuire, 2015). WHO and the World Bank reiterate that the degree to which people lacks financial protection or suffers from catastrophic health expenditure (CHE) can be estimated by focusing on OOP payment made by the people especially those with lower SES. As the healthcare cost inflates annually with the development of chronic diseases, especially ESRD, the unprecedented expenditure on healthcare may lead the renal transplant recipient and household into CHE and poverty.

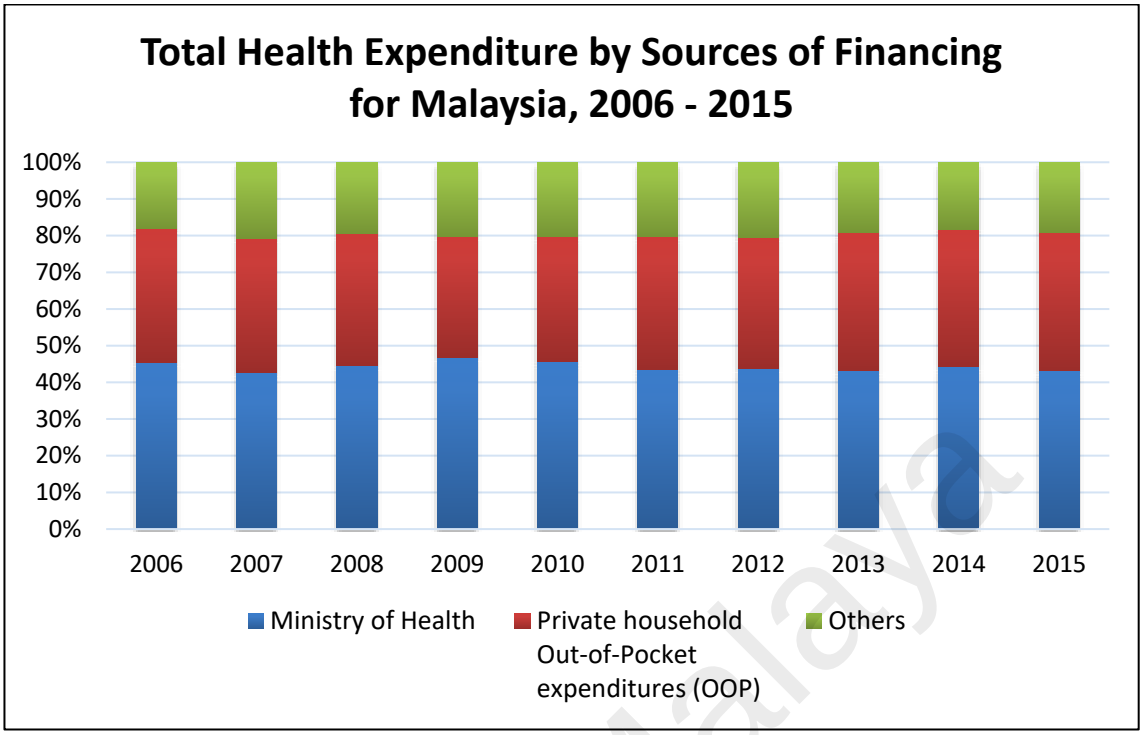


Figure 2.14: Total health expenditure in percentage by the source of financing for Malaysia from 2006 – 2015
Source: (Ministry of Health Malaysia, 2017)

In Malaysia, 58.2% out of the total healthcare expenditure is subsidized by the government while the rest is made up of private insurance, OOP payment and unaccounted private financing (World Health Organization, 2006). As a whole, the Malaysian population utilizes their household income as the primary source for their healthcare financing (Ministry of Health Malaysia, 2015). It was corroborated by data from (Ministry of Health Malaysia, 2017) which indicated that the household OOP expenditure remains the largest single source of funding from 1997 to 2015. Figure 2.14 shows that household OOP payments contributed between 32% to 38% of the total healthcare expenditure in Malaysia over a decade from 2006 – 2015.

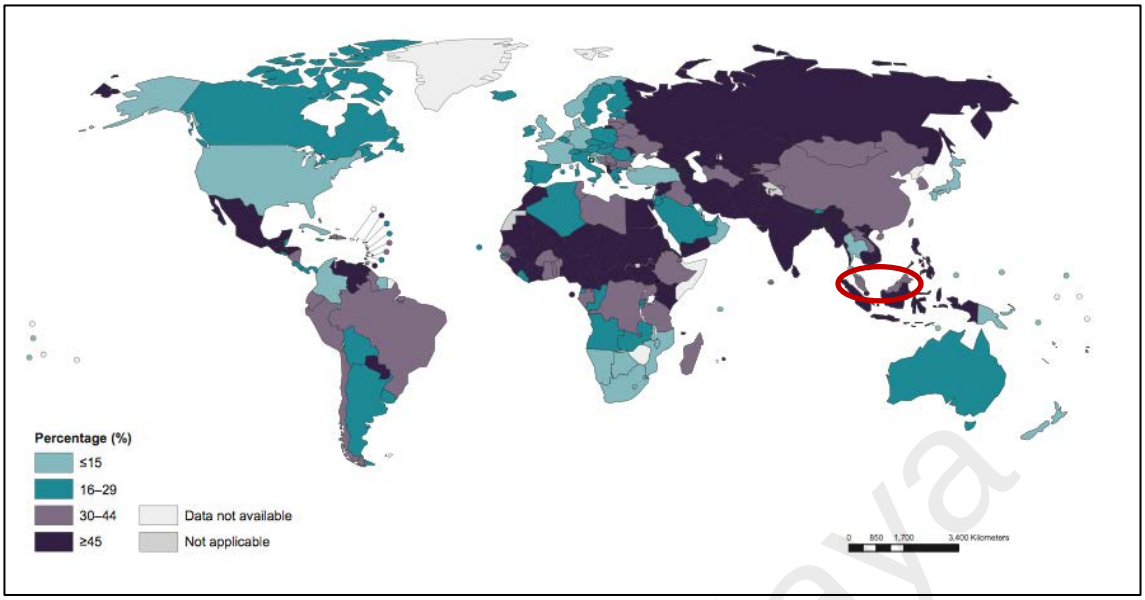


Figure 2.15: Out-of-pocket payment on health as a percentage of total expenditure in health for 2013
Source: (World Health Organization, 2015)

OOP payments remain the most significant contributor of private healthcare expenditure in Malaysia with an average of 78% in 2015 (Ministry of Health Malaysia, 2017) which is nearly double the percentage reported in high-income countries as illustrated in Figure 2.15. Research by Yu et al. indicated that the OOP payments are concentrated among the population in the wealthiest income quintile of Malaysia with a spending of nearly half (48.45%) of all OOP payments paid, while the population in the poorest income quintile spent less than 10% (9.11%) of all OOP (Yu et al., 2006).

However, the latest data indicated that the household OOP payment by population in the poorest income quintile (Q1) on healthcare was ranked second after the population in the wealthiest income quintile (Q5) as demonstrated in Figure 2.16 (Ministry of Health Malaysia, 2015). It indicates that the most deficient 20% of the population is heavily burdened with healthcare expenditure when compared with the rest of the population in Malaysia. Nevertheless, the healthcare financing for post-transplantation management of

renal transplant recipients has not been previously described in Malaysia. Therefore, the financial burden in this context may not be clear.

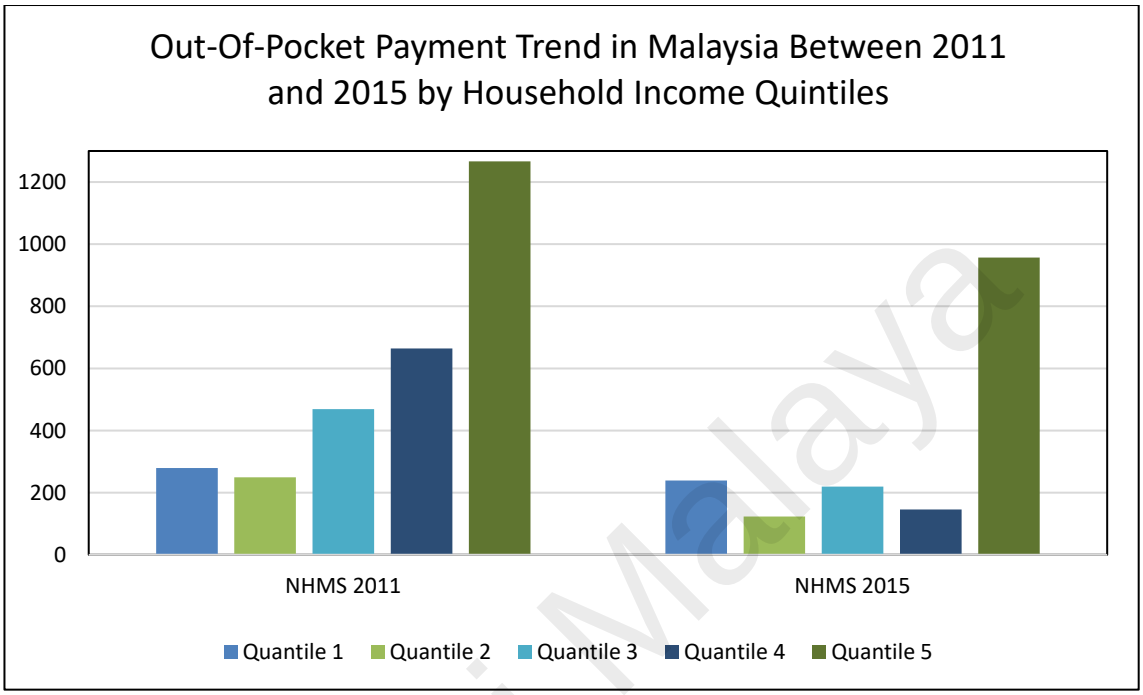


Figure 2.16: Out-of-pocket payment trend in Malaysia by household income quintiles
Source: (Ministry of Health Malaysia, 2011b)
NHMS – National Health and Morbidity Survey

Based on the WHO definition, UHC is not just about providing free financing for any healthcare service because no country would be able to cover all services for free in a sustainable approach. Besides that, UHC encompasses many aspects of the healthcare system besides healthcare financing, for example

1. UHC includes all components of the health system: health service delivery systems, the health workforce, health facilities and communications networks, health technologies, information systems, quality assurance mechanisms, and governance and legislation.

2. UHC is not only about ensuring the healthcare system provides essential health services, but also about ensuring a progressive expansion of coverage of health services and financial protection when more resources are made available.
3. UHC does not refer to just individual care, but also includes population-based services such as public health campaigns, healthy lifestyle campaign – "*10 000 Langkah Sehari*"[1], organ donation campaign – "*Jom Derma*"[2] and so on.
4. UHC comprised of much more than just health; taking steps towards UHC means steps towards equity, development priorities, and social inclusion and cohesion. (World Health Organization, 2017).

2.11 Overview of Malaysia's Environment

2.11.1 Access to Renal Transplantation in Malaysia

World Health Organization (WHO) consider the access to renal transplantation as a complex, multidimensional, and multilevel interaction determined by demographic characteristics, medical treatment as well as the availability of resources such as medical technology and trained healthcare professionals in renal transplant (S. L. White et al., 2014).

[1] Health program to encourage the public to walk 10 000 steps a day

[2] Organ donation campaign that encourages the public to pledge for organ donation

2.11.1.1 Living Renal Transplantation

Any competent, healthy adult can donate a kidney safely for renal transplantation except for (Ministry of Health Malaysia, 2007)

1. Children (defined by the Child Act 2001 as individuals below 18 years old) except for regenerative tissues
2. Individual diagnosed with mental disabled (defined by the Mental Health Act 2001 as any mental illness, arrested or incomplete development of mind, psychiatric disorder or any other disorder or disability of the mind)
3. Prisoners awaiting execution (unless in a life-threatening situation involving close relatives and must be subjected to approval by authority)

According to (Ministry of Health Malaysia, 2011e), individuals who can donate their kidneys as living donors are

1. Living donor with a genetic relationship with the prospective recipients
2. Living donor with an emotional relationship with the prospective recipients. These individuals will have a close personal relationship with the prospective recipient. Examples of emotional relationships
    a) Legal spouse (husband/wife)
    b) Fiancé
    c) Close friend
    d) Adopted children

Table 2.5: Summary of the degree of consanguinity for living donor with a genetic relationship

Degree of consanguinity	Example
First degree relatives	1. Mother 2. Father 3. Daughter 4. Son 5. Full sister (including heterogenous twin / multiple twins 6. Full brother (including heterogenous twin / multiple twins)
Second-degree relative	1. Grandmother 2. Grandfather 3. Granddaughter 4. Grandson 5. Aunt 6. Uncle 7. Niece 8. Nephew 9. Half-sister 10. Half-brother
Third-degree relative	1. Great-grandmother 2. Great-grandfather 3. Great-granddaughter 4. Great-grandson 5. Great-aunt 6. Great-uncle 7. First female cousin 8. First male cousin 9. Grandniece 10. Grandnephew

Source: (Ministry of Health Malaysia, 2011e)

3. Living donor without any relationship (either genetic or emotional) with prospective recipients
    a) Require prior authorisation from the Unrelated Transplant Approval Committee (UTAC)
    b) Must fulfil the following criteria

I. No available deceased donor

II. No compatible donor from genetically-related or emotionally related family members

Each transplant centre has a transplantation unit that will coordinate the living-related renal transplantation to be performed in the centre. The Donor Advocate Team who are independent and are not involved in the organ procurement and transplantation team (to minimize any conflict of interest) must counsel and review all the living donors. The DAT comprises of

1. Donor Advocate: Physician
2. Donor Advocate: Psychiatrist
3. Donor Advocate: Medical social work officer

DAT must evaluate prospective living donor was not induced or coerced into donating and provide the necessary information required regarding the risks, benefits and possible consequences before the donor can make an informed decision. The renal transplant centres that are currently operating in Malaysia are as follows (H. S. Wong & Goh, 2018)

1. Kuala Lumpur Hospital
2. Selayang Hospital
3. University Malaya Medical Centre
4. Prince Court Medical Centre

Any kidney procurement from living donors must be performed at an accredited centre by credentialed healthcare personnel as stipulated in the guidelines. The responsibility to confirm the relationship status between donor and recipient for each case falls to the attending nephrologist. If the genetic relationship is doubtful or difficult to

ascertain, the attending consultant nephrologist must refer the case to UTAC (Ministry of Health Malaysia, 2007). The National Transplant Resource Centre (NTRC) will coordinate the living-related kidney donation process. Under the guidelines, a related kidney donation is not required to undergo review by UTAC, donors who are considered to be related to the prospective recipients are

1. Identical (homozygous) twin
2. First-degree relative
3. Second-degree relative
4. Legal spouse

Nevertheless, for the living unrelated renal donation, the NTRC, together with the Transplantation Unit of the Medical Development Division, will facilitate the application process for the evaluation of UTAC. Furthermore, all living renal transplantation must be reported to the National Transplant Registry. Figure 2.17 shows the types of related and not related living renal donation that requires UTAC approval.

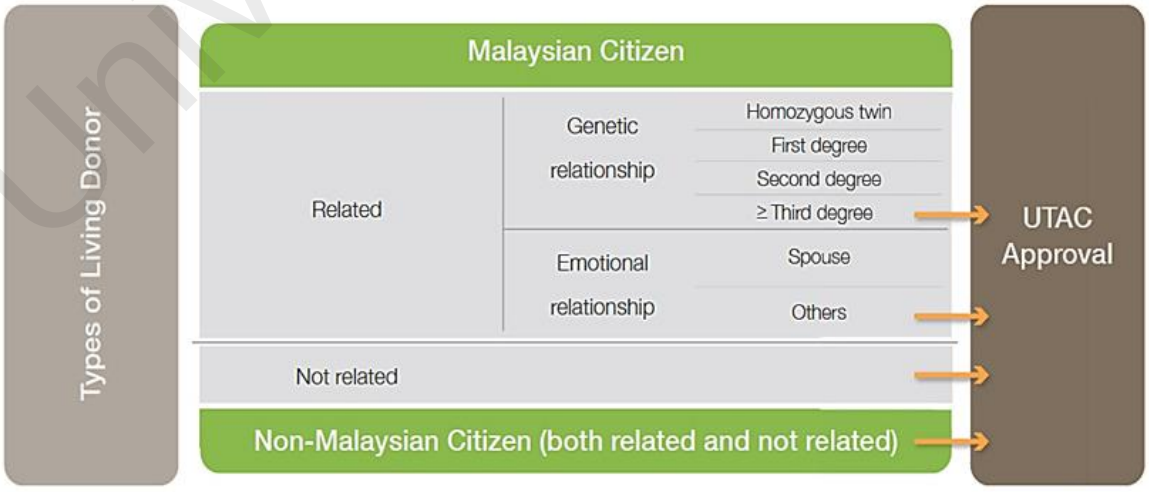


Figure 2.17: Living kidney donation that requires UTAC approval before renal transplantation
Source: (Ministry of Health Malaysia, 2011e)
UTAC, Unrelated Transplant Approval Committee

2.11.1.2 Deceased Transplantation

b. Procurement from Deceased Donor

The Transplantation Procurement Management Unit (TPMU) is a national body tasked to manage and coordinate with the Tissue Organ Procurement (TOP) team from local hospitals all aspect of organ procurement (i.e. kidneys) from deceased donors. Any death is considered a possible organ donation and must be referred to the TOP team. The consent for organ donation is obtained from a family member. However, if a potential deceased donors' remains are being retained under Criminal Procedure Code for a post-mortem or coronal inquest, the court's approval is required before any organ procurement is performed (Ministry of Health Malaysia, 2007).

In cases where the kidneys are not utilised for transplantation, the family member must be consulted on the disposal arrangement or obtain informed consent if the kidneys are to be used for other purposes. An investigation must be conducted if there were any instances when the kidneys are unused, and it must be reported to the National Transplantation Technical Committee (Ministry of Health Malaysia, 2007).

c. Kidney Allocation and Transplantation Waiting List

A collaboration between the Ministry of Health (MOH) and the Malaysian Society of Nephrology (MSN) was undertaken to develop a national organ-sharing network - Malaysian Organ Sharing System (MOSS). The function of this system is to

1. Maintain a list of voluntarily enrolled ESRD patients as potential recipients in the deceased donor renal transplantation
2. Prioritize patients on the waiting list according to standardized criteria

3. Provide a list of matched potential recipients based on standardized criteria when a deceased kidney is available (H. S. Wong, 1999)

The allocation of the kidney is based on national guidelines which take into consideration

1. Donor-Recipient matching criteria
2. Priority according to clinical urgency
3. Duration of waiting time
4. Special cases, e.g. highly sensitised patients and logistic factors
5. Presence of co-morbid conditions (Ministry of Health Malaysia, 2007)

The Transplant Centre performing transplant surgery will have access to the latest updated recipient waitlist ranked according to standardized criteria. On the other hand, the transplant physician and surgeon can view the selected ESRD patients' medical records.

The doctor in charge of the dialysis centre needs to participate in the National Renal Registry to place ESRD patients on the waitlist. The Malaysian Dialysis and Transplant Registry provided a list of participating dialysis centre that tabulate their compliance certificate and whether their annual submission of data was above 80% (H. S. Wong & Goh, 2018). On top of this, only credentialed nephrologists are privileged to place, review or remove patients on the waitlist (Ministry of Health Malaysia, 2007). The waiting time is shorter when live donors are used for transplantation. One reason for the long waiting time is the shortage of kidneys from deceased donors for transplantation.

The MOSS will assign ESRD patients to a nephrologist to manage their waitlist status, to determine the eligibility of ESRD patient for transplant and rank them on the list (H. S. Wong, 1999). Table 2.6 list the inclusion and exclusion criteria for renal transplantation in Malaysia.

Table 2.6: List of inclusion and exclusion criteria for renal transplantation based on MOSS

Inclusion Criteria	Exclusion Criteria
All Malaysian citizens who are medically fit for transplantation	Patients with any disease or illness with an expected survival of fewer than five years or with a resultant poor QOL are not eligible
Permanent residents will be considered on an individual basis	Patients with the follow conditions ▪ Positive HIV serology ▪ Positive Hepatitis B antigen, Active Hepatitis B infection ▪ Active liver disease ▪ Severe cardiovascular / cerebrovascular / pulmonary disease ▪ Dementia or psychosis with no underlying treatable disease ▪ Malignancy with a poor life expectancy ▪ Rare diseases, e.g. Oxalosis (not contraindicated for combined liver and renal transplantation), Fabry's disease ▪ Active substance abuse
Patients between the ages of 2 years and 60 years old	

Source: (H. S. Wong, 1999)
MOSS, Malaysian Organ Sharing System
QOL, Quality of Life
HIV, Human Immunodeficiency Virus

MOSS with the attending nephrologist will determine the candidate's eligibility (life expectancy « 1 year without renal transplant) for the medical emergency list (SOS list) (H. S. Wong, 1999). These candidates on the SOS list will have priority for the deceased renal transplantation. On top of that, ESRD patients below the age of 18 years old will be prioritized.

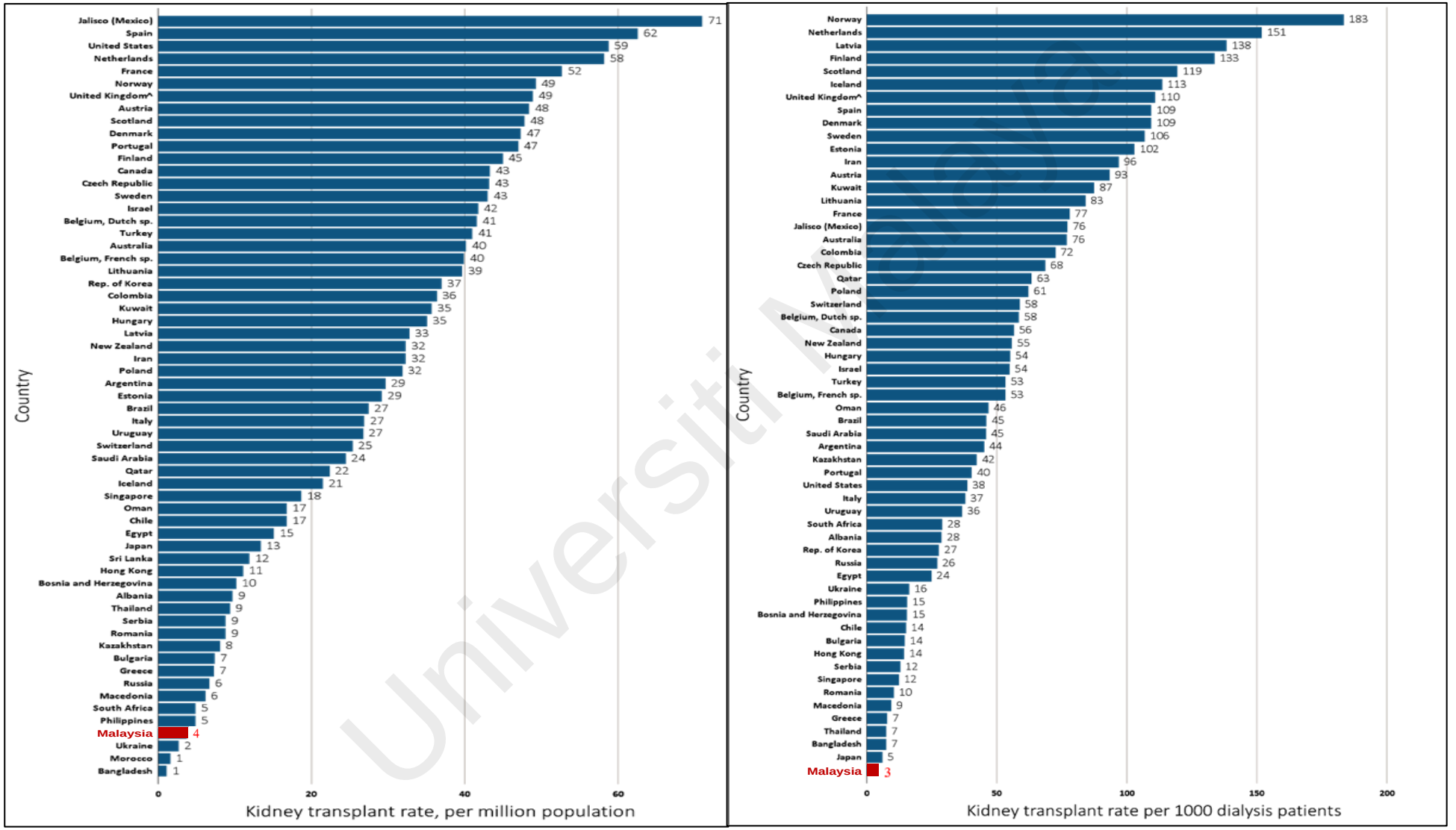


Figure 2.18: Kidney transplant rate per million population and per 1000 dialysis patients, by country, in 2015

Source: (Saran et al., 2018)

Figure 2.18 from the report by Saran et. (2018) compares the rate of renal transplantation across countries in 2015. Malaysia recorded a 1295 ESRD patients per million population similar to the estimates from Canada, Chile, France, Greece, Israel, Belgium and Spain (refer figure 2.1). The standardized rates of ESRD and transplant rates, allowed the comparison between the countries demonstrating that these countries have a better transplant rate compared to Malaysia's four renal transplantation per million population. The high number of dialysis patients in Malaysia contributed to the drop in ranking of renal transplant rate when it was based on 1000 dialysis patients making Malaysia the last in the list of 59 countries.

Although Chile, Spain, France and Israel have a similar prevalence rate of ESRD compared to Malaysia, these countries have explicit opt-out legislation that is used by the government to increase the rate of organ donation in their country (Zúñiga-Fajuri, 2015). Evidence has shown that presumed consent (opt-out) does increase donation rates by 25 to 30% than those in countries requiring explicit consent (opt-in) (Davidai et al., 2012; Rithalia et al., 2009). Other reasons mentioned for the higher transplantation rates in these countries may be due to their high-income status with better transplantation infrastructure, healthcare spending, donor registries and public attitudes towards renal transplantation (Bilgel, 2012).

2.11.2 Legal and Policy Framework on Renal Transplantation in Malaysia

The world rallied in unison to legislate and prevent commercial organ trafficking and tourism by adopting the Declaration of Istanbul in 2008. Malaysia as one of the signatories took proactive actions against organ tourism by criminalizing organ trading to decrease the organ sale around the world by

a. removing subsidies for immuno-suppressive drugs (Director-General of Health Malaysia, 2011)
b. collaborating with other government – China to phase out organ harvest from executed prisoners (Jha, 2015) and international organizations
c. developing better systems of deceased organ donation (e.g. reforming existing law as indicated by the Ministry of Health that would preserve the ethical and professional practices in human organs and tissues transplantation in Malaysia) (Fazaniza, 2016)
d. encouraging altruistic living kidney donation; all living kidney donors will be admitted to the first-class ward and will be exempted from paying the hospital charges at any public hospitals (Director-General of Health Malaysia, 2013). It is an indirect monetary incentive because no cash payments are made directly to the organ donors.

   The direct monetary incentive in the Iranian model (1988) is heavily regulated and funded by the government with the help of a third-party organization, the Dialysis and Transplant Patients Association (DTPA) (R. W. Major, 2008). The government will compensate the donor with a net payment for their organ, if the donor demands for more than what is offered, the recipient will pay the difference (Karakayali & Haberal, 2005). Furthermore, renal transplant recipients will receive subsidized immunosuppression medication, while organ donors receive free health insurance in addition to the payment (R. W. Major, 2008). Non-Iranian ESRD patients are not allowed to receive organs from Iranian donors to avoid 'true transplantation tourism' and international exploitation.

e. preventing the need for renal transplantation by treating diseases that lead to organ failures such as diabetes and hypertension, for example (Hooi, Wong, et al., 2005; Ministry of Health Malaysia, 2016a)

I. Prevention of renal failure workshops targeted at primary care doctors

II. Opportunistic screening at health clinics

III. Public education targeting high-risk groups

IV. Reduce modifiable risk factors for non-communicable diseases

V. Promote high-quality research and development for the prevention and control of non-communicable diseases

VI. Empowering the public through KOSPEN

KOSPEN (*Komuniti Sihat Perkasa Negara*) is a national-level healthy community program, to encourage the public to adopt a healthy lifestyle by training volunteers from the local community are trained to perform simple health screenings (Chung et al., 2017).

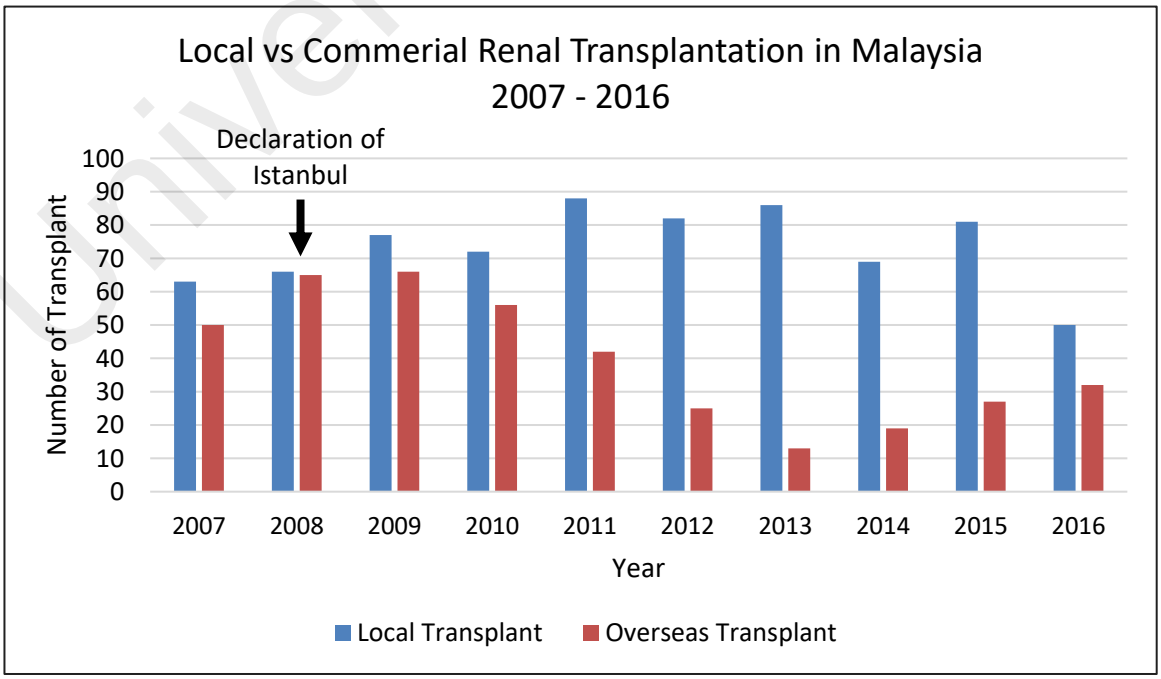


Figure 2.19: Local and commercial renal transplantation performed in Malaysia, 2007 – 2016

Source: (H. S. Wong & Goh, 2018)

Figure 2.19 shows the impact of the Declaration of Istanbul on the commercial renal transplantation in Malaysia from 2007 – 2016. The Declaration has been able to reduce steadily the ability of patients to undergo commercial transplant outside Malaysia. However, this trend seems to have reversed since 2014 with a gradual rise in the commercial transplant. Like many countries globally, the demand for kidneys in Malaysia far exceeds the supply. However, the practice of commercial transplantation shows an shows an innate link with the inability of national healthcare systems to meet the needs of ESRD patients coupled with poor regulation and implementation (S. L. White et al., 2008). With the prohibition of organ sale and tourism, the MOH needs to encourage organ donation from living and deceased donors in Malaysia as dictated by National Organ, Tissue and Cell Transplantation Policy 2007. Unfortunately, to date, there is only 1% of the Malaysian population who have pledged their organs according to the National Transplant Resource Centre, and the renal transplantation from live donors has been deteriorating from 2005 to 2015, at 41 cases and 31 cases respectively (H. S. Wong & Goh, 2016).

The Malaysian Human Tissue Act 1974 is the primary legislation in the country that governs the procurement of organs (i.e. kidneys) from cadavers for therapeutic, medical education and research purposes. However, no legislation governs living donor transplantation in Malaysia except for guidelines from the Ministry of Health Malaysia. The Ministry of Health is proposing a new law that will make the commodification of human organs, tissues and, advertising for that purpose illegal. It will also ensure that there is no element of exploitation or coercion for living donation (Fazaniza, 2016).

The “opt-in” system currently practised in Malaysia requires that the donors provide informed consent before a person’s organ can be donated. The organ procurement team may proceed to harvest the organs upon the death of the donor or if circumstances allow

for procurement. Besides that, doctors are required to take into account the immediate family member of the deceased (Malaysian Medical Council, 2006b). Currently, there are only two options in which deceased organs can be procured in Malaysia ("Human Tissue Act," 1974)

1. Donors providing their consent in writing at any time or verbally during the last illness in the presence of two witnesses (this practice is known as opting in)
2. The person who is lawfully in possession of the deceased body may consent to the removal of the organs

This law is simple and contains only five sections which were legislated based on the Human Tissue Act 1961 of England (Kassim, 2010). It is undefined on the part of who is the "person lawfully in possession of the body", and it did not provide a clear scope and hierarchy of relatives who claim to be a family member of the deceased. It would be opened to interpretation as to who can claim the deceased body because, in a multi-cultural society like Malaysia, relatives with authority to decide will vary with different cultures (Kassim, 2010).

Even though an express request was made by the deceased for organ donation, the final decision whether the organ (i.e. kidneys) can be procured falls on the "person lawfully in possession of the body". It is in line with the Act, which states that "person lawfully in possession of the body" retains the discretion to refuse the organ removal because he either believed that the deceased had expressed an objection to his body being dealt so with after his death *or* that the surviving spouse or any surviving family member of the deceased objects to the organ donation ("Human Tissue Act," 1974).

The refusal of family member to allow organ donation of the deceased has resulted in the reduced deceased transplantation rate in Malaysia (Kassim, 2005). In the United

Kingdom, a similar system is practised that allows the families' wishes to be respected, which override 505 eligible registered donor since 2012 (Naylor, 2017). Consequently, England is considering implementing a soft opt-out approach (i.e. if the family objects, the organ procurement will not occur) for organ donation following the Welsh system that was introduced in 2015. This opt-out system assumes that the people will have deemed to have consented to the removal of their organs unless they expressed otherwise. However, the flexible approach of this system allows the family member to be consulted if they possess evidence to suggest that the deceased have opposed to organ donation and were unable to actively opt-out before their death ("Human Transplantation (Wales) Act," 2013). It is in contrast to the current system, which allows the family member to dictate the decision of whether organs are donated even if it means overriding the known wishes of the potential donor.

Turkey shares a similar history with Malaysia by having the first live donor renal transplantation being conducted in 1975 (Karakayali & Haberal, 2005; Ministry of Health Malaysia, 2007). On top of that, both countries' population are predominantly Muslim. They have religious authorities (e.g. Turkish Religious Affairs Supreme Council and Malaysian Department of Islamic Development) who produce "fatwa". The fatwa states that organ donation is permissible under Islamic law, and it is encouraged to be practised (Aykas et al., 2015; Ministry of Health Malaysia, 2011c).

The similarity ends here because Turkey has improved her transplantation rate tremendously with 41 renal transplants per million population as compared to Malaysia's four renal transplants per million population with a prevalence of ESRD of 935 per million population and 1295 per million population respectively in 2015 as illustrated in Figure 2.10 (Saran et al., 2018). Bas et al. researched to show an exponential increase in the number of publications on renal transplantation that was produced between three

periods; from 1980 to 1989, from 1990 to 1999 and between 2000 and 2009 (Bas et al., 2011). During the latest period, Turkey was ranked 11th globally for renal transplantation publications. How did Turkey progress so well when both countries (Malaysia and Turkey) started together at the same time?

Based on Karakayali & Haberal, Turkey had no law that governed organ donation initially (Karakayali & Haberal, 2005). The success of the first renal transplantation made national headlines in television, radio and newspapers and allowed the public to visualise the outcome of renal transplantation who are healthy recipients. With the public support, members of Parliament, officials in the Department of Religious Affairs and the Ministry of Health, and other governmental institutions banded together to write a law on harvesting, storage, grafting, and transplantation of organs and tissues was enacted in 1979. The government legalized transplantation without consent in medical emergencies in 1980, whereby the organs are procured from donor bodies that are damaged terribly after accidents or disasters (Dogan, 2016). Subsequently, Turkey has been actively engaging in this field by establishing The Turkish Organ Transplantation and Burn Treatment Foundation in 1980 and the Middle East Society for Organ Transplantation (MESOT) in 1987 to advance the interests in organ transplantation.

The National Coordination Centre (NCC) was established by the Turkish Ministry of Health to promote transplantation activities, especially for deceased donor organ procurement and building 28 transplant centres with modern, contemporary, fully equipped facilities with well-trained surgeons for renal transplantation. From statistics, between 1974 and 2004, a total of 6686 renal transplant surgeries were performed with the living donor transplantation overshadowing the deceased donor transplantation with 75.7% and 23.3% respectively (Karakayali & Haberal, 2005). It could be explained by

the fact that the Turkish community is a very tight family-oriented society and the majority of the living donors are the parents of the recipients (Carim, 2001).

Table 2.7 summarizes the legislation and guidelines locally and internationally that affects renal transplantation in Malaysia. Renal transplant laws and policies that govern renal transplantation in Malaysia do not exist in a vacuum. Actions taken in one domain may have unintended or undesired consequences in another. It may also have synergistic, positive effects in other areas, for instance, decisions about education, transportation or organ donation and treatment subsidies affect health outcomes of ESRD patients positively, negatively or both.

Table 2.7: Summary of legislation & guidelines on renal donation & transplantation applicable in Malaysia

	Legislation / Guidelines	Description
Malaysian Law	Human Tissue Act 1974 [Act 130]	Authorisation of removal of human tissues from a cadaver – by express consent or by consent of the person lawfully in possession of the deceased body or magistrate has written approval for medico-legal cases
	Anti-Trafficking in Person and Anti- Smuggling of Migrants Act 2007 [Act 670]	Avoid "exploitation" of a trafficked person or migrant which includes the removal of their organs by force
	Private Healthcare Facility and Services Act 1997 [Act 586]	Governs the licensing and approval of any private healthcare institution to provide transplantation services
	Medical Act 1972 [Act 50]	Code of Professional Conduct and Malaysian Medical Council guidelines on organ transplantation

"Continued"

Table 2.7: Summary of legislation & guidelines on renal donation & transplantation applicable in Malaysia (continued)

	Legislation / Guidelines	Description
Malaysian Policy	Nephrology Service Operational Policy 2010 (Ministry of Health Malaysia, 2010)	Covers vital areas of nephrology services such as organization, human resource, asset requirements, patient management, ethics and clinical governance, which include RRT.
	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Guide practitioners in the field and other stakeholders to further develop renal transplantation to treat ESRD
	Unrelated Living Organ Donation: Policy and Procedure 2011 (Ministry of Health Malaysia, 2011e)	Limiting related living organ donation to legal spouse and 2nd-degree relatives & below. Unrelated living organ donation requires MOH approval
	Circular on the Supply of Immunosuppressant 2011 (Director-General of Health Malaysia, 2011)	Immunosuppressant subsidy removal for transplant tourism among RTRs. To discourage cross boundaries, unethical practices, exploitation and crime.
	Circular on public hospital bill exemption and first-class admission for living organ donors 2013 (Director-General of Health Malaysia, 2013)	Living organ donors shall receive free post-transplantation treatment and admitted in first-class in any government hospitals.
	MMC Guideline on Organ Transplantation 2006 (Malaysian Medical Council, 2006b)	Ethical issues in organ transplantation relate to organ donation and organ allocation.
	MMC Guideline on Brain Death 2006 (Malaysian Medical Council, 2006a)	Ethical considerations for doctors in diagnosing and certifying brain death for organ donation
International Policy	WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation (Sixty-Third World Health Assembly, 2010)	
	Declaration of Istanbul on Organ Trafficking and Transplant Tourism 2008 (The Transplantation Society and International Society of Nephrology, 2014)	

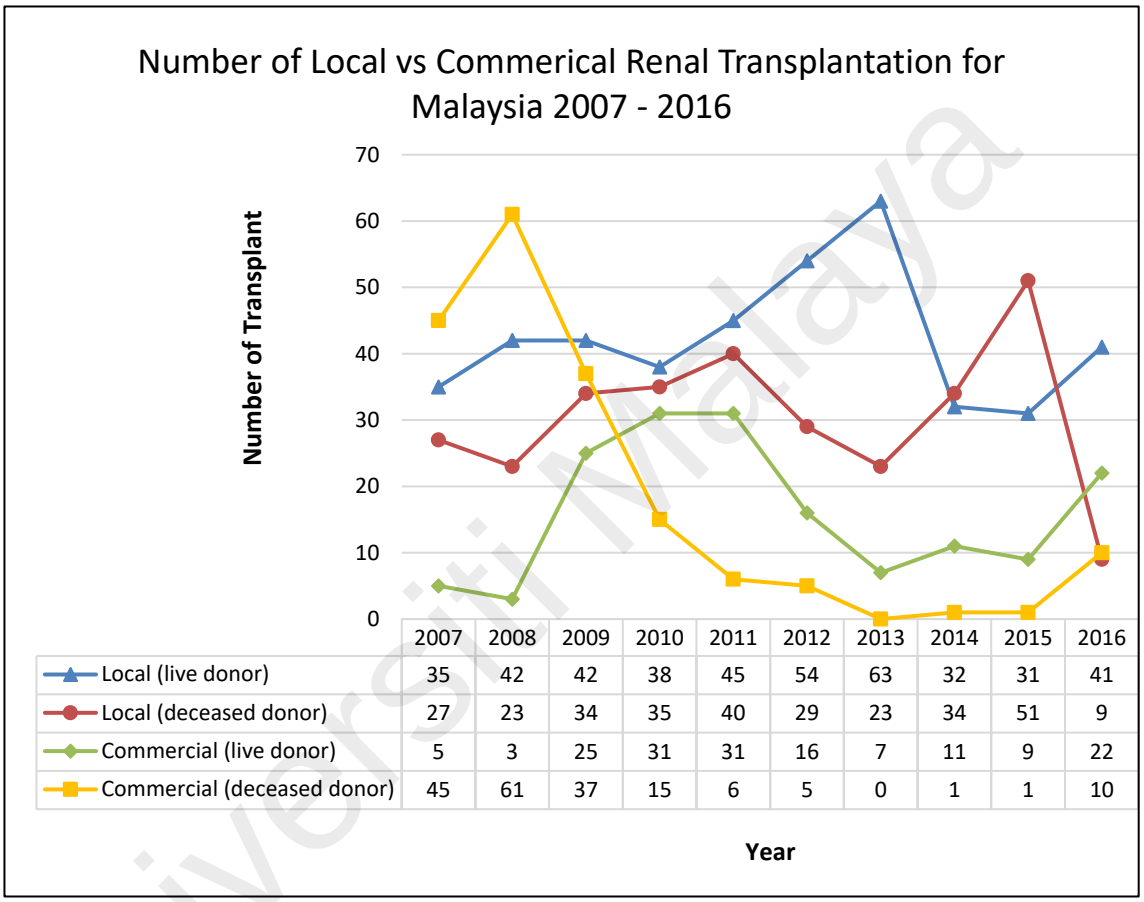
2.11.3 Transplantation Modalities of ESRD Patients in Malaysia

As described in the earlier section, ESRD patients have options to undergo a living-related renal transplant or a deceased transplant in Malaysia. A living-related kidney transplant will be a faster alternative if the family member agrees to donate his/her kidney. However, ESRD patient who does not have the option of living donor renal transplant may wait upwards of 8 to 10 years for a deceased donor kidney in Malaysia. With a plateau rate of new renal transplant recipient at 3 or 4 per million population over the last 10 years, the transplantation rate per million population would also decrease as a result (H. S. Wong & Goh, 2018). It would be more significant if it were compared to the number of dialysis patients on the waiting list, which has doubled over the 10 years. Wong et al. emphasized that the average waiting time for a renal transplant which was already very long is now at least three folds the norm (H. S. Wong & Goh, 2018).

This disparity between the supply and demand of deceased organs and the difficulties of getting a live-related donor renal transplantation has led many ESRD patients to leave Malaysia for other countries to obtain a renal transplant and avoid prolonged waiting times. The ESRD patients can be purchasing either a live-unrelated donor (commercial live donor) or a deceased donor source (commercial deceased donor). These two forms of transplantation have dominated the local transplantation scene since the 1990s to the 2000s creating a negative impact on the local live related donor programme.

Kokubo highlighted several factors that facilitated the practice of commercial transplantation that may be applicable in Malaysia's context (Kokubo, 2009). The reasons identified were because of rapid globalization due to air travel and free access of information; poor cooperation between countries to implement international and

transnational laws; and the widening socioeconomic gap within and between population leading to exploitation. The implication of commercial renal transplantation has raised many ethical and legal issues in Malaysia since its inception.



	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Local (live donor)	35	42	42	38	45	54	63	32	31	41
Local (deceased donor)	27	23	34	35	40	29	23	34	51	9
Commercial (live donor)	5	3	25	31	31	16	7	11	9	22
Commercial (deceased donor)	45	61	37	15	6	5	0	1	1	10

Figure 2.20: Number of local vs commercial renal transplantation for Malaysia from 2007 – 2016
Source: (H. S. Wong & Goh, 2018)

Figure 2.20 shows the trend of renal transplantation performed locally and overseas for Malaysia over the past decade. The number of transplantations performed locally is relatively unchanged except for commercial deceased transplantation with a sharp decline in 2008 while commercial live transplantation increased from 2008 – 2011 before falling over the next few years. There is a worrying trend of rising commercial renal transplantation that requires investigation.

2.12 Review of Renal Transplantation Practices in Malaysia

At the 63rd World Health Assembly (WHA), the World Health Organization (WHO) Guiding Principles on Human Cell, Tissue and Organ Transplantation with guidance on regulatory, ethical and medical strategies on human organ and transplantation was adopted (World Health Assembly, 2010). The pertinent recommendation that followed from the assembly was that all member states must maximize donation from deceased donors and to ensure that essential healthcare services and long-term follow-up are provided to maintain the health and welfare of living donors. It could be achieved by improving the regulations, ethical practices as well as the science of organ donation and transplantation of every country. A robust organ transplantation process is necessary to ensure that the deceased and living organ donation programmes are

1. transparent in practice by ensuring autonomy, anonymity and privacy of donors and recipients
2. surgical procedure is of high-quality, safe and efficacious
3. organ allocation must be based on clinical criteria and ethical norms, not by financial consideration
4. organ trading and exploitation of humans must be prevented and penalized

Malaysia hosted the WHO Regional Office for Western Pacific Malaysia in 2009 with 19 participating countries on human organ transplantation. It showed that Malaysia is committed to implementing the recommendations proposed by WHO to combat against the commercialisation of human organ and organ trafficking as well as transplant tourism. All member states reviewed and unanimously endorsed the WHO Guiding Principles on Cell, Tissue and Organ Transplantation and characterized it as a benchmark that all national policies and programmes should conform.

The Ministry of Health Malaysia, together with Malaysian Transplantation Society, have also endorsed the Declaration of Istanbul on Organ Trafficking and Transplant Tourism 2008 (The Transplantation Society and International Society of Nephrology, 2014). The declaration will encourage countries to develop legislation and guidelines to prevent the unethical practices of human organ trading and exploitation of vulnerable groups like the poor and executed prisoners for their organs. Malaysia, on her part, has been drafting a new law on organ transplantation to ensure the ethical practices is following the highest international standards (Director-General of Health Malaysia, 2014).

Besides that, White et al. has developed a framework for reducing the burden of ESRD and improving equity of access to RRT (includes renal transplantation) by targeting on

1. International environment (excluded because ReTRAPP focus is on Malaysia only)
2. Local legislation, regulation and policy
3. Community
4. Health system and health professionals (S. L. White et al., 2008)

White further elaborated that local governance is vital to regulate or engage relevant stakeholders to ensure the development of efficacious policy initiatives, and subsequently effective policy implementation mechanisms for the success of renal transplantation (S. L. White et al., 2008). The progress of Malaysia's renal transplantation program was reviewed by examining the current national policy of kidney donation and transplantation in Malaysia that were available with the WHA Resolution in Table 2.8 for and the current national strategies based on the framework proposed by White in Table 2.9.

Table 2.8: Malaysian progress based on recommendations from the World Health Assembly

Item	World Health Assembly Resolution on human organ donation and transplantation	Documentation	Notes
1	Implement the Guiding Principles on Human Cell, Tissue and Organ Transplantation in the formulation and enforcement of their own policies, laws and legislation regarding human cell, tissue and organ donation and transplantation where appropriate	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Guideline and policy prepared before the endorsement of the update WHO guideline in 2011. No update on policy ad guideline ***No mention of WHO guideline***
		MMC Guideline on Organ Transplantation 2006 (Malaysian Medical Council, 2006a)	
		Unrelated Living Organ Donation: Policy and Procedures 2011 (Ministry of Health Malaysia, 2011e)	WHO guideline was referenced in this policy
2	Promote the development of systems for the altruistic voluntary non-remunerated donation of cells, tissues and organs as such, and increase public awareness and understanding of the benefits as a result of the voluntary non-remunerated provision of cells, tissues and organs as such from deceased and living donors, in contrast to the physical, psychological and social risks to individuals and communities caused by trafficking in material of human origin and transplant tourism.	Circular on public hospital bill exemption and first-class admission for living organ donor 2013 by Director General of Health (Director-General of Health Malaysia, 2013)	No-remuneration of organ donation but living organ donors will receive free post-transplantation treatment and shall be admitted in first class.
		Organ donation website (National Transplant Resource Center, 2017)	Information centre for the community to inquire about organ donation and transplantation in Malaysia.
		Patient's Education MyHEALTH Ministry of Health Malaysia (Ministry of Health Malaysia, 2016b)	

"Continued"

Table 2.8: Malaysian progress based on recommendations from the World Health Assembly

Item	World Health Assembly Resolution on human organ donation and transplantation	Documentation	Notes
3	Oppose the seeking of financial gain or comparable advantage in transactions involving human body parts, organ trafficking and transplant tourism, including by encouraging healthcare professionals to notify relevant authorities when they become aware of such practices in accordance with national capacities and legislation	Circular on Supply of Immunosuppressant 2011 by Director General of Health (Director-General of Health Malaysia, 2011)	Immunosuppressive therapy not subsidized to RTRs who procured their organs overseas to discourage transplant tourism
		Anti-Trafficking in Person Act 2007 [Act 670]	Prevents exploitation of persons and migrants that contravenes the law or human organ transplants
		Human Tissue Act 1974 [Act 130]	***Current legislation does not mention transplant tourism.*** New Organ and Tissue Transplantation Bill proposed. It will include selling and buying of human organs, tissues and, advertising for that purpose illegal
4	Promote a system of transparent, equitable allocation of organs, cells and tissues, guided by clinical criteria and ethical norms, as well as equitable access to transplantation services in accordance with national capacities, which provides the foundation for public support of voluntary donation	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	The national transplantation waiting list is in place - MOSS. Deceased kidney allocation is done in a fair, equitable and transparent manner
		Malaysian Organ Sharing System (H. S. Wong, 1999)	

"Continued"

Table 2.8: Malaysian progress based on recommendations from the World Health Assembly

Item	World Health Assembly Resolution on human organ donation and transplantation	Documentation	Notes
5	Improve the safety and efficacy of donation and transplantation by promoting international best practices	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Outline the accreditation, credentialing and standards for centres and healthcare personnel including organ procurement and transplantation laboratory services
		Nephrology Service Operational Policy 2010 (Ministry of Health Malaysia, 2010)	
6	Strengthen national and multinational authorities and/or capacities to provide oversight, organization and coordination of donation and transplantation activities, with special attention to maximizing donation from deceased donors and to protecting the health and welfare of living donors with appropriate health-care services and long-term follow up	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	The policy includes organ and tissue procurement process of the deceased kidney. It also dictates that all living organ donors shall be followed up for life with free post-transplantation treatment at any government hospital
		Circular on organ and tissue procurement service 2008 by Director General of Health (Director-General of Health Malaysia, 2008)	
		Circular on public hospital bill exemption and first-class admission for living organ donor 2013 by Director General of Health (Director-General of Health Malaysia, 2013)	
7	Collaborate in collecting data including adverse events and reactions on the practices, safety, quality, efficacy, epidemiology and ethics of donation and transplantation	Annual Report on Malaysian Dialysis and Transplant Registry (MDTR) (H. S. Wong & Goh, 2018)	Collect information on patients with ESRD on RRT which include renal transplant in Malaysia

Table 2.9: Malaysian strategies compared to the Framework proposed by While et al. (2008)

Item	Strategic framework for reducing the burden of ESRD and improving equity of access to RRT (focus on renal transplantation)	Documentation	Notes
Target on Local Legislation, Regulation and Policy on Renal Transplantation			
1	National register of dialysis and transplant patients	Annual Report on Malaysian Dialysis and Transplant Registry (MDTR) (H. S. Wong & Goh, 2018)	Collect information on patients with ESRD on RRT which include renal transplant in Malaysia
2	Integrated programmes of chronic vascular disease prevention	National Strategic Plan for Non-Communicable Diseases (NSP-NCD) 2016-2025 (Ministry of Health Malaysia, 2016a)	Outline the strategies based on Global Action Plan for the Prevention and Control of NCDs to address risk factors (i.e. tobacco use, unhealthy diet, physical inactivity and harmful use of alcohol) and sets out directions that prevent and control NCD (i.e. for cardiovascular diseases, diabetes and cancer) with the emphasis on whole-of-government and whole-of-society approach
3	Facilitate local manufacture of generic derivatives of immunosuppressive medications	Renal Pharmacy Service Guideline 2011 (Ministry of Health Malaysia, 2010)	***No mention of the promotion of local manufacturing of generic derivatives of immunosuppressive therapy.***

NCD, Non-communicable disease

"Continued"

Table 2.9: Malaysian strategies compared to the Framework proposed by While et al. (2008)

Item	Strategic framework for reducing the burden of ESRD and improving equity of access to RRT (focus on renal transplantation)	Documentation	Notes
Target on Local Legislation, Regulation and Policy on Renal Transplantation			
4	Retention of skilled personnel	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	***No mention of skilled personnel retention***. Outline that ▪ human resource committee to determine requirements and develop training for allied health personnel ▪ training committee to accreditate sites and credential trainers; monitor training programs ▪ standards determined and reviewed by appropriate professional bodies or societies appointed/recognised by MOH
		Nephrology Service Operational Policy 2010 (Ministry of Health Malaysia, 2007)	
5	National planning of renal transplant delivery, policies regarding eligibility	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Brief outline of the organ allocation and transplantation waiting list
		Nephrology Service Operational Policy 2010 (Ministry of Health Malaysia, 2010)	Outlines briefly the delivery, policies regarding the eligibility of deceased renal transplant via MOSS

ESRD, End-Stage Renal Disease
RRT, Renal Replacement Therapy
MOSS, Malaysian Organ Sharing System
MOH, Ministry of Health

"Continued"

Table 2.9: Malaysian strategies compared to the Framework proposed by While et al. (2008)

Item	Strategic framework for reducing the burden of ESRD and improving equity of access to RRT (focus on renal transplantation)	Documentation	Notes
Target on Local Legislation, Regulation and Policy on Renal Transplantation			
6	Oversight and regulation of organ procurement and transplantation processes	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Outlines organ procurement
		Patient's Education MyHEALTH Ministry of Health Malaysia (Ministry of Health Malaysia, 2016b)	Provides information on renal transplantation processes and procurement
		Organ Donation website (National Transplant Resource Center, 2017)	
5	Develop policy regarding organ donation and transplantation	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Outlines national policy on organ transplantation
		Nephrology Service Operational Policy 2010 (Ministry of Health Malaysia, 2010)	Outlines briefly the delivery, policies regarding the eligibility of deceased renal transplant via MOSS

ESRD, End-Stage Renal Disease
RRT, Renal Replacement Therapy
MOSS, Malaysian Organ Sharing System

"Continued"

Table 2.9: Malaysian strategies compared to the Framework proposed by While et al. (2008)

Item	Strategic framework for reducing the burden of ESRD and improving equity of access to RRT (focus on renal transplantation)	Documentation	Notes
Target on Local Legislation, Regulation and Policy on Renal Transplantation			
7	Develop policy regarding organ donation and transplantation	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Outlines national policy on organ transplantation
		Living Organ Donation. What You Need to Know… 2011 (Ministry of Health Malaysia, 2011a)	Outlines national policy on living organ donation
		Unrelated Living Organ Donation 2011 (Ministry of Health Malaysia, 2011e)	Outlines national policy on unrelated organ donation
8	Effective implementation mechanisms for policy	Nephrology Service Operational Policy 2010 (Ministry of Health Malaysia, 2010)	Outlines the renal transplantation services briefly in MOH facilities

ESRD, End-Stage Renal Disease
RRT, Renal Replacement Therapy
MOH, Ministry of Health

"Continued"

Table 2.9: Malaysian strategies compared to the Framework proposed by While et al. (2008)

Item	Strategic framework for reducing the burden of ESRD and improving equity of access to RRT (focus on renal transplantation)	Documentation	Notes
	Target on Community		
1	Public education to raise awareness of vascular disease and its risk factors	National Strategic Plan for Non-Communicable Disease (NSPNCD) 2016-2025 (Ministry of Health Malaysia, 2016a)	Provides an outline for *KOmuniti Sihat PEmbina Negara* (KOSPEN) initiative that empowers the community to be involved in public health programs like healthy eating, active living and health screening.
2	Lifestyle interventions	National Strategic Plan for Non-Communicable Disease (NSPNCD) 2016-2025 (Ministry of Health Malaysia, 2016a)	Outlines policy on ▪ National Plan of Action for Nutrition of Malaysia (NPANM) III 2016-2025 ▪ National Strategic Plan for Tobacco Control 2015-2020 ▪ Policy Options to Combat Obesity in Malaysia 2016-2025 ▪ Salt Reduction Strategy to Prevent and Control NCD For Malaysia 2015-2020 ▪ National Strategic Plan for Active Living 2016-2025 ▪ Malaysia Alcohol Control Action Plan 2013-2020

ESRD, End-Stage Renal Disease
RRT, Renal Replacement Therapy

"Continued"

Table 2.9: Malaysian strategies compared to the Framework proposed by While et al. (2008)

Item	Strategic framework for reducing the burden of ESRD and improving equity of access to RRT (focus on renal transplantation)	Documentation	Notes
	Target on Community		
3	Vascular risk screening (focus on NCDs because the major cause of ESRD is mainly due to diabetes mellitus and hypertension)	National Strategic Plan for Non-Communicable Disease (NSPNCD) 2016-2025 (Ministry of Health Malaysia, 2016a)	Outlines the objective to monitor the trends and determinants of NCDs and evaluate progress in their prevention and control by ▪ Monitoring ▪ Disease registries ▪ Surveillance ▪ Capacity strengthening in surveillance and monitoring ▪ Dissemination and use of results
4	Public education to increase support for organ donation	Patient's Education MyHEALTH Ministry of Health Malaysia (Ministry of Health Malaysia, 2016b)	Provides public education on organ donation
		Organ Donation website (National Transplant Resource Center, 2017)	Provides public education on organ donation
5	A role for non-governmental organizations in the above strategies	National Kidney Foundation Malaysia (National Kidney Foundation Malaysia, 2017)	Limited information on kidney transplant and organ donation. The emphasis in on dialysis modality.

ESRD, End-Stage Renal Disease
NCD, Non-Communicable Disease
RRT, Renal Replacement Therapy

"Continued"

Table 2.9: Malaysian strategies compared to the Framework proposed by While et al. (2008)

Item	Strategic framework for reducing the burden of ESRD and improving equity of access to RRT (focus on renal transplantation)	Documentation	Notes
Target on Health System and Health Professionals			
1	Develop locally appropriate deceased donor transplant programmes	Nephrology Service Operational Policy 2010 (Ministry of Health Malaysia, 2010)	Outlines briefly the organization of deceased donation activity
2	Continuing education of health professionals	Nephrology Service Operational Policy 2010 (Ministry of Health Malaysia, 2010)	Indicates that consultant and clinical nephrologist required to organize and participate in continuous medical education in the department
3	Capacity building of workforce	Nephrology Service Operational Policy 2010 (Ministry of Health Malaysia, 2010)	Outlines the establishment of Nephrology Training Committee to ▪ Formulating, reviewing and updating the Ministry of Health training programme ▪ Identify potential overseas training centres and collaborate ▪ Monitoring the trainees and training programme

ESRD, End-Stage Renal Disease
RRT, Renal Replacement Therapy

"Continued"

Table 2.9: Malaysian strategies compared to the Framework proposed by While et al. (2008)

Item	Strategic framework for reducing the burden of ESRD and improving equity of access to RRT (focus on renal transplantation)	Documentation	Notes
Target on Health System and Health Professionals			
4	Centralize organ procurement procedures	Nephrology Service Operational Policy 2010 (Ministry of Health Malaysia, 2010)	Outlines that a dedicated unit (TPMU) at the national level is established to manage and coordinate all aspects of organ procurement from deceased donors
5	Utilize private and non-governmental sources of funding	***Not Available***	-
6	Promote cost-effective and locally appropriate technologies	***Not Available***	-

ESRD, End-Stage Renal Disease
RRT, Renal Replacement Therapy
TPMU, Transplantation Procurement Management Unit

During the Third Global Consultation on Organ Donation and Transplantation, World Health Organization (WHO) has urged member countries to be self-sufficient in meeting the organ donation and transplantation needs of their populations. It outlines strategies to reduce demand (by reducing chronic diseases that cause ESRD) and increase supply (promoting living-related kidney donation besides deceased kidney donation) (World Health Organization, 2011). ReTRAPP would like to evaluate the preparedness of Malaysia to self-sufficient in renal transplantation by

1. preventing the need for transplantation and increasing organ availability are national responsibilities
2. donation and transplantation reflect comprehensive health care
3. opportunities to donate should be provided in as many circumstances of death as possible

Table 2.10 shows the assessment of Malaysia's preparedness for self-sufficiency in renal transplantation based on the Madrid Resolution.

Table 2.10: Malaysian preparedness for self-sufficiency based on recommendations from the Madrid Resolution

Item	Madrid Resolution on human organ donation and transplantation	Documentation	Notes
Preventing the Need for Transplantation and Increasing Organ Availability Are National Responsibilities			
1	Organ donation and transplantation have a role in the national health policies, regardless of current transplant capability	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Outline the renal transplantation services briefly in MOH facilities
2	Of equal importance to infrastructure and professional development in organ donation and transplantation is sustained investment in prevention to reduce future needs for transplantation, through intervention in the major risk factors for end-stage organ failure and the development of health systems able to meet the challenges of chronic diseases such as diabetes, cardiovascular disease (CVD), and hepatitis.	National Strategic Plan for Non-Communicable Disease (NSPNCD) 2016-2025 (Ministry of Health Malaysia, 2016a)	Outlines objective prevention to reduce future needs for renal transplantation by ▪ reducing modifiable risk factors for NCDs and underlying social determinants through health-promoting environments ▪ strengthening and orientating health systems to address the prevention and control of NCDs and the underlying social determinants through people-centred primary health care and universal health coverage
3	National transplantation legislation consistent with the WHO Guiding Principles is fundamental. It provides adequate protection from exploitation and unethical practices and eliminates legislative impediments constraining the science and medicine of donation from deceased persons.	Human Tissue Act 1974 [Act 130]	***Legislation not updated to WHO Guiding Principles***. New Organ and Tissue Transplantation Bill is proposed. It will be consistent with WHO Guiding Principles that will provide an orderly, ethical and acceptable framework for the acquisition and transplantation of human cells, tissues and organs for therapeutic purposes.

NCD, Non-communicable Disease
WHO, World Health Organization

"Continued"

Table 2.10: Malaysian preparedness for self-sufficiency based on recommendations from the Madrid Resolution

Item	Madrid Resolution on human organ donation and transplantation	Documentation	Notes
Preventing the Need for Transplantation and Increasing Organ Availability Are National Responsibilities			
4	Public support for organ donation necessitates normative change. To this end, education of the public should begin in school, emphasizing individual and community ethical values such as solidarity and reciprocity. Self- sufficiency is founded in three main ethical premises: ▪ The human right to health encompasses transplantation and disease prevention. ▪ Organs should be understood as a social resource; equity must, therefore, govern both procurement and allocation. ▪ Organ donation should be perceived as a civic responsibility.	Malaysia Education Blueprint. 2013–2025 (Ministry of Education Malaysia, 2013)	Outlines a brief strategy by the Ministry of Education on inculcating ethics and spirituality on students to advance them to a high level of personal well-being who appreciates sustainable development and a healthy lifestyle. ***No mention on organ transplantation specifically***
		Patient's Education MyHEALTH Ministry of Health Malaysia (Ministry of Health Malaysia, 2016b)	information on renal transplantation processes and prevention of ESRD provided. ***No mention on ethics of transplantation***
		Organ Donation website (National Transplant Resource Center, 2017)	

ESRD, End-Stage Renal Disease

"Continued"

Table 2.10: Malaysian preparedness for self-sufficiency based on recommendations from the Madrid Resolution

Item	Madrid Resolution on human organ donation and transplantation	Documentation	Notes
Donation and Transplantation Reflect Comprehensive Health Care			
1	The critical functions of oversight, maintenance of professional standards and ethics, regulation, policy setting, and monitoring and evaluation of organ donation and transplantation programmes are most effectively managed by a National Transplant Organization (NTO).	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Outline the renal transplantation services briefly in Ministry of Health facilities on oversight, maintenance of professional standards and ethics, regulation, policy setting, and monitoring and evaluation of organ donation and transplantation
2	Data registries are necessary for operational support (waiting list management and organ allocation) and for monitoring and surveillance of practices and outcomes.	Malaysian Organ Sharing System (McPherson et al.) (H. S. Wong, 1999)	The national transplantation waiting list is in place – using Malaysian Organ Sharing System. Deceased kidney allocation based on distributive justice and medical suitability
3	Monitoring and surveillance should encompass the following data: national prevalence and incidence of end-stage organ failure and diseases contributing to end-stage organ failure (need); availability of related infrastructure and access to organ replacement therapies; outcomes of organ replacement therapy; acceptance onto transplant waiting lists and time to receipt of an organ; organ donation practices, standards and activities; practices, standards and activities in organ donation from living persons; and outcomes of transplantation (patient and graft survival).	Annual Report on Malaysian Dialysis and Transplant Registry (MDTR) (H. S. Wong & Goh, 2018)	Provide annual prevalence and incidence of ESRD and diseases contributing to ESRD, the outcome of RRT, the outcome of renal transplantation (patient and graft survival).
		Living Organ Donation. What you need to know… 2011(Ministry of Health Malaysia, 2011a)	Outline the standards and activities in related or unrelated organ donation from living persons in Malaysia
		Unrelated Living Organ Donation: Policy and Procedures 2011 (Ministry of Health Malaysia, 2011e)	

ESRD, End-Stage Renal Disease; RRT, Renal Replacement Therapy

"Continued"

Table 2.10: Malaysian preparedness for self-sufficiency based on recommendations from the Madrid Resolution

Item	Madrid Resolution on human organ donation and transplantation	Documentation	Notes
Opportunities to Donate Should Be Provided in as Many Circumstances of Death as Possible			
1	The critical pathway provides a framework for the process of donation from deceased persons, which will aid global harmonization of practice.	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Outlines briefly the activity of deceased organ donation
2	The key to self-sufficiency is maximizing donation from deceased persons: facilitating donation in as many circumstances of death as possible, maximizing the outcomes from each donor, and optimizing the results of transplantation. Donation after both brain death and circulatory death should be regarded as ethically proper. Organ donation from living persons should be encouraged as complementary to donation after death by providing appropriate regulatory frameworks and donor care.	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Outlines potential deceased donations shall be made known to the local TOP team and all deaths considered for organ donations.
		MMC Guideline on Brain Death 2006 (Malaysian Medical Council, 2006a)	Outlines the ethical consideration; for diagnosing and certifying brain death for organ donation
		Living Organ Donation. What you need to know… 2011 (Ministry of Health Malaysia, 2011a)	Provides information on living organ donation
		Unrelated Living Organ Donation: Policy and Procedures 2011 (Ministry of Health Malaysia, 2011e)	
3	Physicians and nurses involved in acute care have a central role in identifying possible donors and facilitating donation after death, and therefore should be supported by the necessary educational, technical, legal and ethical tools to assume leadership in this regard within their facility.	National Organ Tissue and Cell Transplantation Policy 2007 (Ministry of Health Malaysia, 2007)	Provide information on TOP Team that must be trained but do not specify acute care personnel. ***No mention of educational, technical, legal and ethical tools***

TOP, Tissue Organ Procurement

As indicated from the reviews, Malaysia has fulfilled most of the criteria in the WHA's Resolution on human organ donation and transplantation. It also fulfilled the criteria in the strategies proposed on reducing the burden of ESRD and improving equity of access to RRT, indicating the ethical and legal practice of renal transplantation in Malaysia that meets international standards. On top of this, the Madrid resolution, which assesses the self-sufficiency of renal transplantation demonstrates that Malaysia satisfied most of the standards for the health system for renal transplantation. Some of the issues face by the transplantation service in Malaysia based on the two Resolutions, and one strategic framework are as follows

1. Malaysian legislation was not revised to reflect the current global transplantation practices
2. Inadequate training and retaining healthcare professionals that are involved in renal transplantation services.
3. The education system does not emphasize or specifically mention organ donation as a civic responsibility.
4. No incentives to produce generic immunosuppressive medications locally to make renal transplantation more cost-effective.

It must be noted that the Resolution (World Health Assembly, 2010) and the Strategies (S. L. White et al., 2008) are established to provide a legislative and ethical guide for countries to perform organ transplantation. These guidelines do not emphasize or advocate organ transplantation (renal transplantation in this context) as the preferred treatment of organ failure (renal failure). Therefore, the conformant to these guidelines would not promote renal transplantation in Malaysia even though other countries have similar healthcare infrastructure (Barber et al., 2017; Saran, Robinson, et al., 2017). However, the three documents would help policymaker to understand the significant

issues that are affecting the renal transplantation system in Malaysia, which can be improved.

The number of ESRD patients in Malaysia is predicted to reach 100,000 in 2040. The preferred choice of renal replacement therapy for these patients should be renal transplantation because it offers better survival, quality of life and cost-effectiveness when compared to dialysis as proven by many kinds of research done locally or abroad. A review or revision of the current kidney donation, procurement and transplantation system is necessary to improve access to renal transplantation in Malaysia for equity and the betterment of the population's health. Without prioritizing renal transplantation as an essential treatment for ESRD, the patients suffering from ESRD would face the prospect of worsening morbidity and mortality under the current status quo.

2.13 Conceptual Framework

The focus of ReTRAPP is to contribute to the knowledge of renal transplantation by resolving a complex policy problem and adopting a pragmatic, problem-solving, holistic approach in dealing with the low transplantation rate. The research questions were framed based on the approach that would consider the effects of socioeconomic status of renal transplant recipients on access and outcome of transplant as well as the renal transplantation policy in Malaysia. Figure 2.21 shows the conceptual framework that was constructed based on currently available literature.

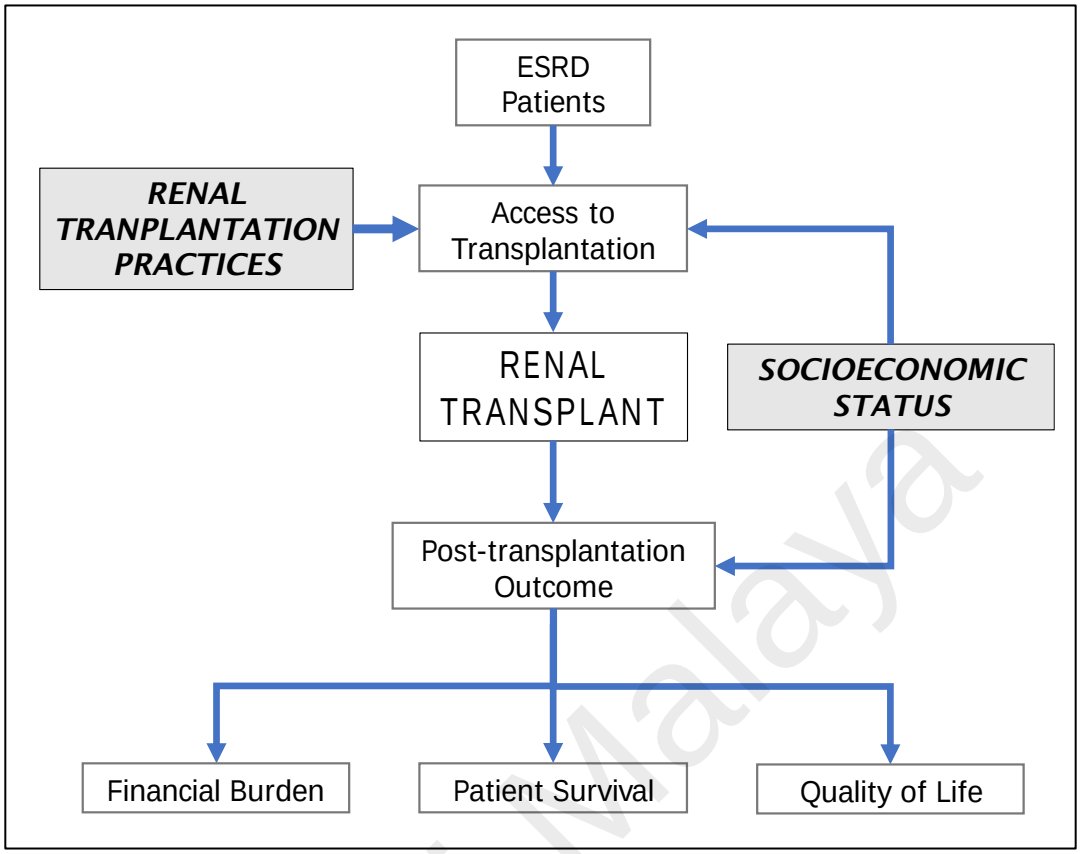


Figure 2.21: ReTRAPP conceptual framework

2.14 Theoretical Framework

ReTRAPP aimed to contribute to resolving a complex policy or practice issue of renal transplantation and took a practical, problem-solving, multidisciplinary approach. The qualitative research question required an approach that could consider all aspects of health policy and human practices. A systemic perspective was needed to approach a complex issue about cause and effect to understand better the influences that should be taken into consideration (Scott & Baehler, 2010). This approach suggested by Scott and Baehler (2010), centred on the "understanding what the issue is" and developing a range of strategies to overcome the issue. It widens the options available by allowing the identification of other stakeholders or factors contributing to the issue rather than always directing it to the doctor. Socioecological model (SEM) was widely employed to

understand and identify factors for both general and specific health behaviour interventions (McLeroy et al., 1988; Stokols, 1996).

SEM began with the ecological system theory, which was used to figure out human development (Bronfenbrenner, 1977, 1979). Reciprocal interactions between end-stage renal disease (ESRD) patients and their environment are the primary stimuli for the outcome and access of renal transplantation. To understand the renal transplantation process, an examination of multilayer systems of interaction that is not limited to a single setting which will take into account the environmental aspects beyond that of the immediate loci of the ESRD patient (Bronfenbrenner, 1977).

Therefore, ReTRAPP adopted the SEM framework by Kumar et al. to study the access to renal transplantation at a multi-level influence to describe the connections between some of the themes identified in the qualitative component (Kumar et al., 2018). SEM is a visual depiction of dynamic relationship derived from systems orientation to human development, in which patients are understood to influence, and be influenced by, people and organizations with whom they interact, available resources and institutions, and societal norms and rules (Bronfenbrenner, 1992).

Access to renal transplantation does not involve only one individual. However, it involves multiple individuals that influence renal transplantation process, and it is essential to recognize the impact that surrounding influences have on the individual. It was emphasized by Sallis et al. and was adopted in the renal transplantation context in Malaysia whereby

1. elements at each level of the model affect health behaviours of the ESRD patients, and a well-developed model will dictate how these elements interact

2. Various environmental factors will have a direct and indirect effect on the ESRD patients' behaviour by influencing their perceptions on renal transplantation
3. These behaviour specific factors will be the leading elements in the socio-ecological model (Sallis et al., 2015)

Therefore, ReTRAPP incorporated these interwoven relationships between individuals and institutions as well as the multi-level of decision-making in the healthcare system to understand the complexity of the issue (Waterman & Rodrigue, 2009). In other words, SEM demonstrates that ESRD patients are influenced by multiple factors of the physical environment such as geography and technology as well as a social environment like family, culture and politics. The levels in SEM are as follows

1. individual (renal transplant recipient, who is at the centre of the framework. It accounts for patient's feel, thoughts and decision-making process on their treatment options, whether and how they decide to consider renal transplantation, as well as the information and knowledge they possessed)
2. interpersonal (family members, who are the potential donors for a given patient or who are the decision-maker to allow the procurement of organ from the deceased. It would be essential to know their knowledge, motivation and opportunity for donation. They are the primary source of support for patients in managing their post-transplant care and navigating through the healthcare)
3. community (cultural believes and norms, the media and public awareness and preferences have a vast influence on other levels of the model)
4. institutional (medical doctors who make decisions about renal replacement therapy for ESRD patients and who manage the patient undergoing renal transplant surgery and post-transplant care)

5. system (decision-makers and advisors, district, state and federal policies and legislation)

SEM served as a framework to help explain the influence of the environmental and policy factors on patient behaviours in the many studies related to renal transplantation such as

1. medication compliance or adherence (Marsicano et al., 2015; C. L. Russell et al., 2016; Silva et al., 2016)
2. racial disparity (McSorley et al., 2017; Rodrigue et al., 2012; Waterman et al., 2010; Wenceslao et al., 2016)
3. transplant education to ESRD patients (McSorley et al., 2017)
4. RTRs' perception of high-risk renal donors (Gordon et al., 2012)
5. RTRs' health disparities (Harding et al., 2017)

To understand the issues surrounding renal transplantation and implement interventions to improve the rate of transplantations, SEM was adopted as an organizing framework to explore factors related to the access of renal transplantation system in Malaysia with emphasis on the development of health-related policies and environment (Arriola, 2017). Utilizing a theoretical context to ReTRAPP was an essential step in researching how key-informants perceive the barriers and solutions to renal transplantation. Figure 2.22 shows a diagram of SEM that would be utilized for the qualitative component of ReTRAPP.

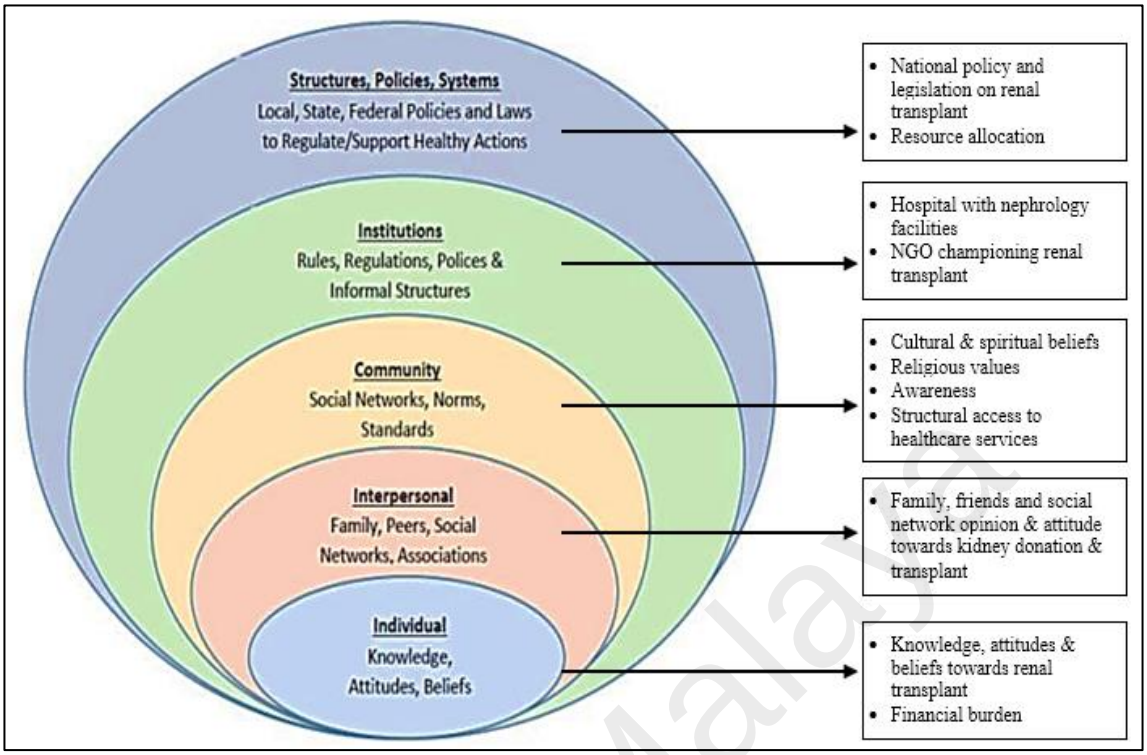


Figure 2.22: Socio-ecological model framework to study access to renal transplantation in Malaysia
Adopted from (Kumar et al., 2018)

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter begins with the methodological approach of ReTRAPP, which seeks to understand the factors affecting the access and outcome of renal transplantation in Malaysia's context. Considering the under-researched population of the renal transplant recipients in Malaysia, both quantitative and qualitative research approaches were undetaken to answer the research questions with the ReTRAPP project.

A combination of qualitative and quantitative approaches in ReTRAPP provided opportunities to generate feasible and high quality data that complement more traditional quantitative research designs (Creswell & Clark, 2007). Two distinct analytical, sequential approaches are applied in ReTRAPP simultaneously, whereby both the quantitative and qualitative data collection and analysis were conducted because they were independent of each other. The qualitative methods of ReTRAPP provide additional information on access to renal transplantation practices and policy which may not be known by the renal transplant recipients. The quantitative methods of ReTRAPP seek to determine the association between the waiting time to renal transplantation and post-transplantation outcome of survival, quality of life and financial burden with the socioeconomic status of renal transplant recipients.

The chapter is divided according to the different approaches; qualitative study as well as two distinctive quantitative studies by retrospective longitudinal cohort study and multi-centre cross-sectional study to answer ReTRAPP's objectives. The chapter will conclude with the general ethical considerations for the entire ReTRAPP research with ethics approval from relevant ethics committees.

3.2 Overview of ReTRAPP

Table 3.1: Summary of ReTRAPP

Study type	Study Design	Description
Qualitative	In-depth interviews with key-informants	A qualitative study involving in-depth interviews with key opinion leaders in renal transplantation. The key-informants provided insight on the current practices, barriers and solutions to renal transplantation in Malaysia.
Quantitative	Retrospective longitudinal observational study	This component included a retrospective longitudinal cohort study of all adult RTRs who have had renal transplantation performed between January 2002 and December 2011. This information was extracted from the Malaysian Dialysis and Transplant Registry (MDTR) of National Renal Registry, Malaysia. This component provided information on the access as well as the graft and patient survival of all renal transplant recipient.
Quantitative	Multi-centre cross-sectional study	This component was conducted using a self-administered survey on renal transplant recipients in publicly funded hospitals in Greater Kuala Lumpur. The survey comprised of 3 parts ▪ Socio-demographic data ▪ Outcome measure of QOL using WHOQOL-BREF survey ▪ Outcome measure of the financial burden

QOL, Quality of Life
WHOQOL-BREF, World Health Organization Quality of Life-100's shortened version

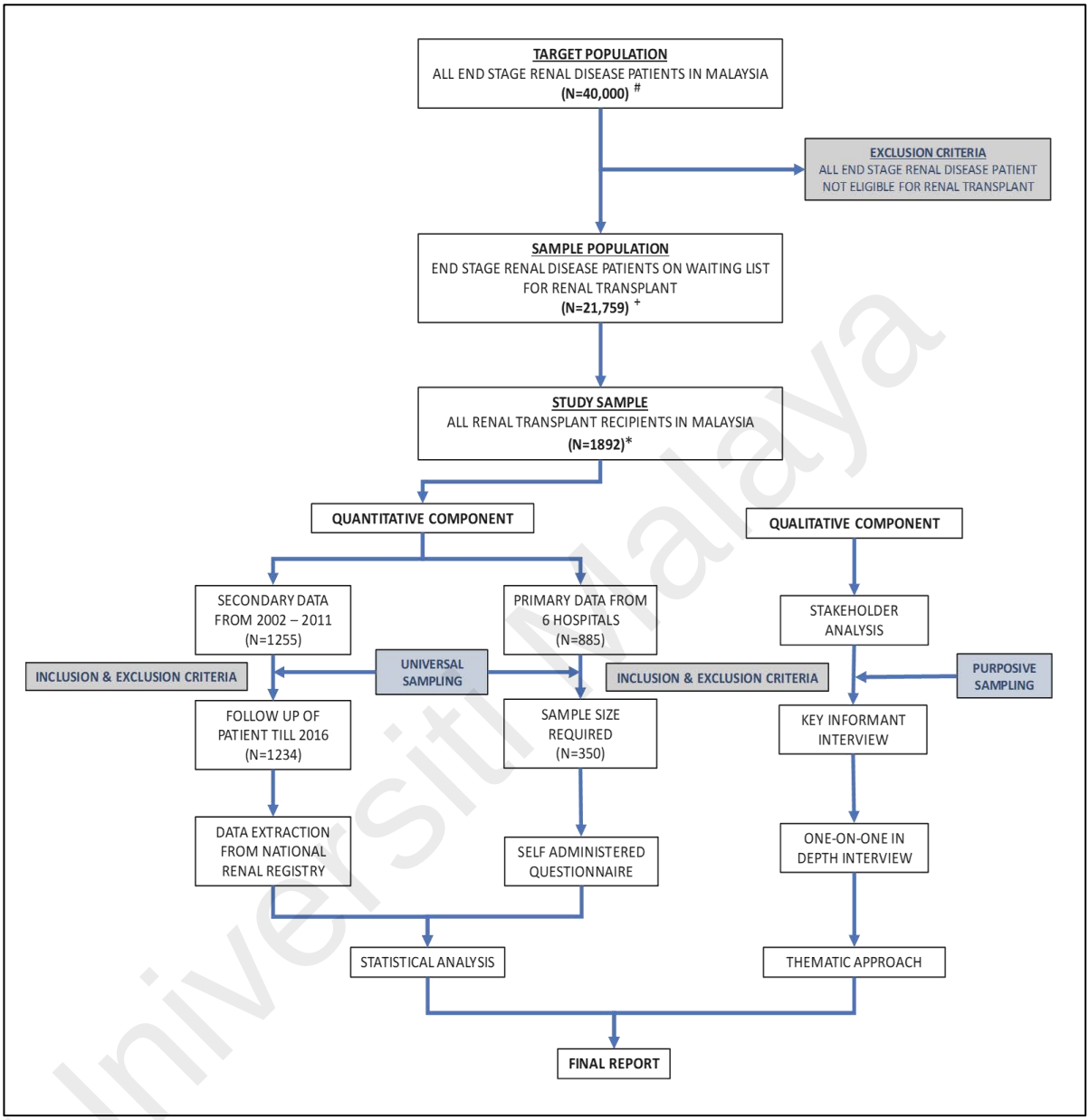


Figure 3.1: Flowchart to summarize ReTRAPP study

Source: (Meikeng, 2017)

+ Source: (Farhana Syed Nokman, 2017)

* Source: (Ngu, 2018)

3.3 Perceived Barriers and Solutions to Renal Transplantation in Malaysia

3.3.1 Study Design

Utilizing the socioecological model (SEM) as a theoretical framework, a qualitative thematic analysis approach was used to describe key-informants' perception of the barriers and solutions to access renal transplantation in Malaysia. One-on-one in-depth interviews were conducted with the key-informants. Key-informants were essential stakeholders in the renal transplantation system in Malaysia.

Qualitative research for transplant is uncommon but is a fundamental approach which contributes considerably in certain areas of research where quantitative research lack (Tong et al., 2013). Qualitative research was adopted to examine social phenomena (i.e. renal transplantation in Malaysia) by offering critical insights into the experience and perspectives of key-informants when information on it is limited. Tong et al. demonstrated that qualitative studies had advanced our understanding of inequities in access to transplantation, nonadherence to immunosuppressive regimens, and complex psychosocial outcomes (Tong et al., 2013). Additionally, the exploration of the barriers and solutions to accessing renal transplantation involved emotions that can be best captured through careful probing using the in-depth qualitative interview.

3.3.2 Setting

Marshall emphasised that selection of appropriately knowledgeable key-informants who are engaged in the critical decision-making process must be verified using their credentials To determine the setting of the qualitative component (M. N. Marshall, 1996a). A simple stakeholder analysis was conducted to determine the key-informants that would be suitable. The exhaustive list of stakeholders in renal transplantation was prepared through literature review (Malaysian Medical Council, 2006b; Ministry of Health Malaysia, 2007, 2010, 2011a, 2011e) and was discussed with the academic supervisors as well as other senior healthcare personnel involved in renal transplantation in Malaysia. The Researchers finalized and analysed the list of stakeholders and their role in renal transplantation. The stakeholder analysis adopted the Mendelow's mapping technique (Mendelow, 1981) to determine the interest of each stakeholder to improve the RT system and if they have the authority (Lumsdaine et al.) to do so.

Based on the stakeholder analysis, key-informants were identified from each group in the high power and high-interest category. The setting of the qualitative component of ReTRAPP was confined to Greater Kuala Lumpur after conducting the stakeholder analysis because all the key decision-making entities are based here. Additional consideration was used for determining this setting based on the researcher's personal experience working in the nephrology unit. The key-informants were identified and later approached for participation in the in-depth interview. The key informant interviews would represent each of the categories as follows

1. National Transplant Council
2. Transplantation Unit, Division of Medical Development, Ministry of Health
3. Malaysian Society of Nephrology

4. Malaysian Urological Association
5. Renal transplant researcher
6. National Transplant Resource Centre

Table 3.2: Analysis of key stakeholders of renal transplantation in Malaysia

	Low power	**High power**
Low interest	1. Public 2. Private hospitals 3. Insurance companies	1. Organ donor 2. Media 3. Religious leaders 4. NGO (e.g. National Kidney Foundation) 5. Association of Private Hospital Malaysia 6. Malaysian Society of Anaesthesiologists 7. Malaysian Society of Transplantation 8. Malaysian Medical Association
High interest	1. Hospitals functioning as transplant centres 2. Clinicians 3. Organ Procurement team 4. ESRD patients / RTRS	1. **National Transplant Council** 2. **Transplantation Unit, Medical Development Division, Ministry of Health** 3. **Malaysian Society of Nephrology** 4. **Malaysian Urological Association** 5. **Renal transplant expert / researcher** 6. **National Transplant Resource Centre**

The time and location of in-depth interviews were conducted at the convenience of the key-informants. Scheduling the interview was a challenging task with frequent re-scheduling, because of the other commitments of the key-informants; who are eminent professionals in their fraternity. The in-depth interviews were conducted between February 2018 and May 2018.

3.3.3 Sampling Procedure

The key-informants were selected by purposive sampling method for participation in the one-on-one in-depth interviews. This sampling method was selected to gain meaningful awareness of the experience of a range of key-informants in the renal transplantation system.

Purposive sampling is a common sampling method in qualitative studies to accumulate knowledge from key-informants whose credentials and experience in their fields automatically makes them the key opinion leaders in the area of interest that are uncommonly researched upon (Becker et al., 2012; Mack et al., 2005; Onwuegbuzie & Leech, 2007). Creswell and Becker et al. highlighted that purposive sampling was favourable in research that lacks empirical evidence or documentation (Becker et al., 2012; Creswell, 2013). The selection of a purposive sample was to gather information on renal transplantation that is only known to a certain number of key stakeholders in the population.

3.3.4 Participants

3.3.4.1 Inclusion and Exclusion Criteria

A stakeholder analysis was conducted, defining criteria such as the qualities and background of the key-informants, to ensure the reliability and the competence of the selected key-informants. Other criteria that the key-informants should have

1. A greater understanding of the renal transplantation practices and process
2. A professional (direct or indirect) involvement in renal transplantation

3. A higher capacity to describe those experiences in addition to other related services that are complementary to the renal transplantation service.

Inclusion criteria of the key-informants were:

1. Malaysian
2. Involved directly or indirectly in the renal transplantation system
3. Affiliated with one of the six categories identified in stakeholder analysis
4. Able to converse in Malay or English
5. Able to participant in a one-to-one in-depth interview lasting from 45 – 60 minutes
6. Able to provide consent to participate in research

3.3.4.2 Sample Size

The sample size is determined based on the efficiency of generating enough information to reach data saturation. Data saturation is defined as a point in which no additional new information can be found, and the repetition of information occurs with no new knowledge of the renal transplantation practices (M. N. Marshall, 1996b).

Many factors can determine the sample size in a qualitative study. However, there are no clear guidelines on what constitutes a sufficient sample size. The recommended number of participants required to reach a point where no new data collection reveals no information can range from two to ten participants depending on the type of qualitative research (Boyd, 2001; Creswell, 2008; Morse, 2000; Parse & Rizzo-Parse, 1998). Guest et al. suggested that a sample of six interviews may be sufficient to enable the

development of meaningful themes and useful interpretations (Guest et al., 2006). Furthermore, five or six interviews were said to be sufficient to produce data saturation that allowed to speak of generalities rather than in terms of individual cases (S. E. Baker & Edwards, 2012; B. Marshall et al., 2013; Morse, 2015). As such, ReTRAPP intended to interview six key-informants, one from each category in keeping with the recommendation by Boyd 2001. However, data saturation was not reached until the 7th key informant considering the depth and richness that ReTRAPP had to obtain. To ensure that data saturation was reached, one additional key informant was interviewed, and it confirmed that no additional information was found that brought new insights to the research question.

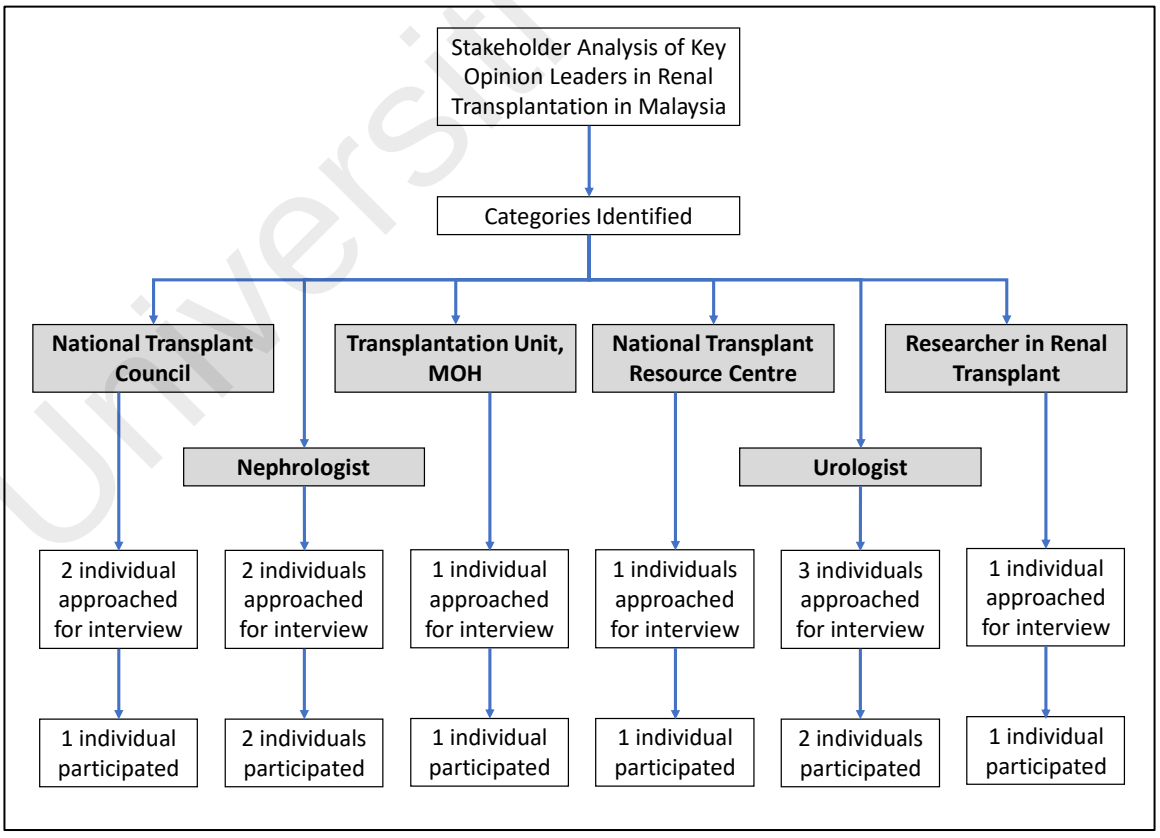


Figure 3.2: Qualitative study participant flowchart

3.3.5 Developing interview protocol

Based on the qualitative objective of ReTRAPP, the key elements were developed to answer the research objectives (Table 3.3).

Table 3.3: Interview questions developed for the qualitative research objective

Research objective	Key Elements
To understand key-informants' perspectives on the **current barriers** on to renal transplantation in Malaysia	1. Issue of end-stage renal disease in Malaysia 2. Issues of renal donation in Malaysia 3. Current organ donation (especially renal) programs and its effectiveness 4. The direction of the renal transplantation program
To explore the experiences of key-informants for **solutions** on how to **improve** the renal transplantation in Malaysia	1. New programs to promote organ donation 2. What can be done as a stakeholder? 3. Update or maintain the current policy and legislation governing renal transplantation 4. Recommendation to improve the transplant rate in Malaysia

The final interview protocol draft was reviewed and revised to ensure that the interview questions are aligned with the research question. Subsequently, the interview protocol was subjected to experts' validation to ensure the interview questions are clear, relevant to the research question and the current context of clinical practice (C. Marshall & Rossman, 2006). The experts consist of two clinical nephrologists; one from the Ministry of Health and another from the Ministry of Education and a researcher with experience in conducting the qualitative study. There were no revisions suggested by the experts. The final interview protocol, as attached in Appendix K, was adopted for the in-depth interview with the key-informants.

3.3.6 Data Collection

The one-on-one in-depth interview was selected as a method of data collection because it allows interviewees to express their perceptions, understandings and experiences in the renal transplantation and can contribute to in-depth data collection. Therefore, in-depth interviews with key-informants involved in renal transplantation in Malaysia was the best approach that gives insight into the transplantation process. They did not just provide insights into renal transplantation system but suggested sources of corroboratory or contradictory information. The method of data acquisition in the qualitative component of ReTRAPP was using open-ended structured questions.

The use of semi-structured interview by incorporating a predetermined set of open-ended questions (essential questions) with ad hoc questions (probing questions) enabled the Researcher to explore the topic that was being studied. A semi-structured interview is the most common method of interview used in exploratory studies, especially for health and social fields (Becker et al., 2012). This method of interview allowed the key-informants' perceptions and experiences to be explored providing reliable, comparable qualitative data (Becker et al., 2012; P. Gill et al., 2008)

The key questions, also known as main questions, were designed to elicit more revealing information about renal transplantation problem, which drew upon the key-informant's expertise and unique viewpoint (Krueger & Casey, 2014). The Key questions provided consistency in all the interviews being conducted, and it enables the Researcher to maintain control of the interview while allowing the key-informants the freedom to express their thought in their own words (Becker et al., 2012).

Additionally, different probing questions were used encouraged the key-informants to reflect more deeply on the meaning of their comments and to elicit the root of the problem in renal transplantation in Malaysia.

3.3.6.1 Interview process

The in-depth interview was initiated by the researcher. At the start of the interview, a brief introduction of ReTRAPP and the purpose of the interview was described to the key informant, and informed consent with few professional details was obtained before commencing the interview. The key-informants were allowed to ask questions before the interview adequately commenced. The key questions were asked, coupled with some probing questions to elicit a more in-depth insight into renal transplantation. The key-informants were encouraged to express their views and opinions on the topic of renal transplantation. The Researcher limited any interference (only prompting for essential and relevant information on renal transplantation policy) during the interview to avoid leading the key-informant's response. The interviews were conducted at the convenience of the key-informants at their preferential time and venue. Although all key-informants were offered an honorarium for their time, however, none accepted it, and none were reluctant to participate in the interview when the issue of no remuneration was brought up.

3.3.6.2 Documentation of the interview

For transcribing purposes, the interview was voice recorded using a digital voice recorder of a mobile phone. The audio-recording allowed the Researcher to engage freely in the interview, without undue interference from making notes. The interviews were conducted in English or Malay. The period of data collection using interviews which were all conducted by the Primary Researcher stretched from early February 2018 – end of May 2018. The estimated time of the interview session ranged from 50 – 70 minutes. When all interviews were digitally recorded and stored in encrypted folders, the Researcher transcribes the interviews verbatim using ATLAS.ti, including any notes that were taken during the interview.

3.3.7 Specific Ethical Considerations

Participation in ReTRAPP study was voluntary. Key-informants were contacted via email for interviews. Key-informants received and acknowledged by signature in the informed consent form (refer Appendix L), which explained both the scope of ReTRAPP and indicated that the key-informant might at any point of time cease participation without any recourse. They were reminded that the interview would be audio-recorded, transcribed verbatim, and that their anonymity would be assured.

ReTRAPP study abides by a strict code of confidentiality and maintains data in a lock protected environment. Key-informants' details were coded from the onset of the project and did not represent any other identifiers. Besides that, other proper names that were mentioned during the interviews were removed or anonymised in situations whereby the removal of the name would affect the presentation of the results (Richards & Morse, 2012). The audio files of the interview were anonymized and stored in an encrypted

folder with each file being password protected. The original audio files were destroyed following the successful conclusion of the ReTRAPP study. Transcripts of the interview were stored following completion of the study as per the site file guideline as described in the section; Retention of Records.

3.3.8 Data Analysis

To ensure the quality of the data, data analysis and the credibility of the findings; Becker (2012) emphasized that the processes for recording the interviews, transcribing the interviews, and using computer-assisted qualitative data analysis software (CAQDAS) must be considered (Becker et al., 2012). ReTRAPP addressed these concerns by

1. Using high-quality digital voice recorder (DVR) on a reputable mobile phone to record the interviews for transcription purposes
2. Transcribing the recorded interviews verbatim and comparing each transcript against the original recording for accuracy. Subsequently, the transcripts were anonymised to protect the identity of the key-informants by converting their name into their initials.
3. The computer-assisted qualitative data analysis software package ATLAS.ti 8 software was used to organise, manage, code, analyse and report the qualitative data.

Qualitative data analysis is the range of processes and procedures whereby we move from the qualitative data that have been collected into some form of explanation, understanding or interpretation of the RTRs and the renal transplantation policy that we are researching (Coffey et al., 1996). The purpose of qualitative data analysis is to

transform and organise the raw data into an improved, rich or developed method that gives meaning to the data (Thorn, 2008). The qualitative analysis provides an abstract or a modified concept of the data with a different approach that will relatable to policymakers and the public alike.

A thematic approach was developed using the research question of ReTRAPP to group the data and then look for similarities and differences. This process is achieved by coding and interpreting the interview data to identify cross-linkages between the key-informants' interview. The coding process involves reading of transcript by Researcher to identify major themes and points of interest, using Atlas.TI, the Researcher, independently codes these interviews based on a thematic framework to categorize data into patterns as the primary basis for organizing and reporting the study findings (C. Marshall & Rossman, 2006). From the qualitative research of ReTRAPP, the data was considerably homogenous, with the key-informants articulating similar findings. Data saturation was achieved after conducting eight key-informants who participated in the one-on-one in-depth interview.

The barriers and solutions for access to renal transplantation in Malaysia were explored using thematic analysis was applied in the qualitative analysis. Creswell's seven-step data analysis is a modification of the descriptive phenomenological method by (Coliazzi, 1978). Figure 3.3 illustrates the qualitative interpretation categorization describes by Creswell, which was adopted to ensure that the data was organized in a meaningful and systematic approach (Creswell, 2008).

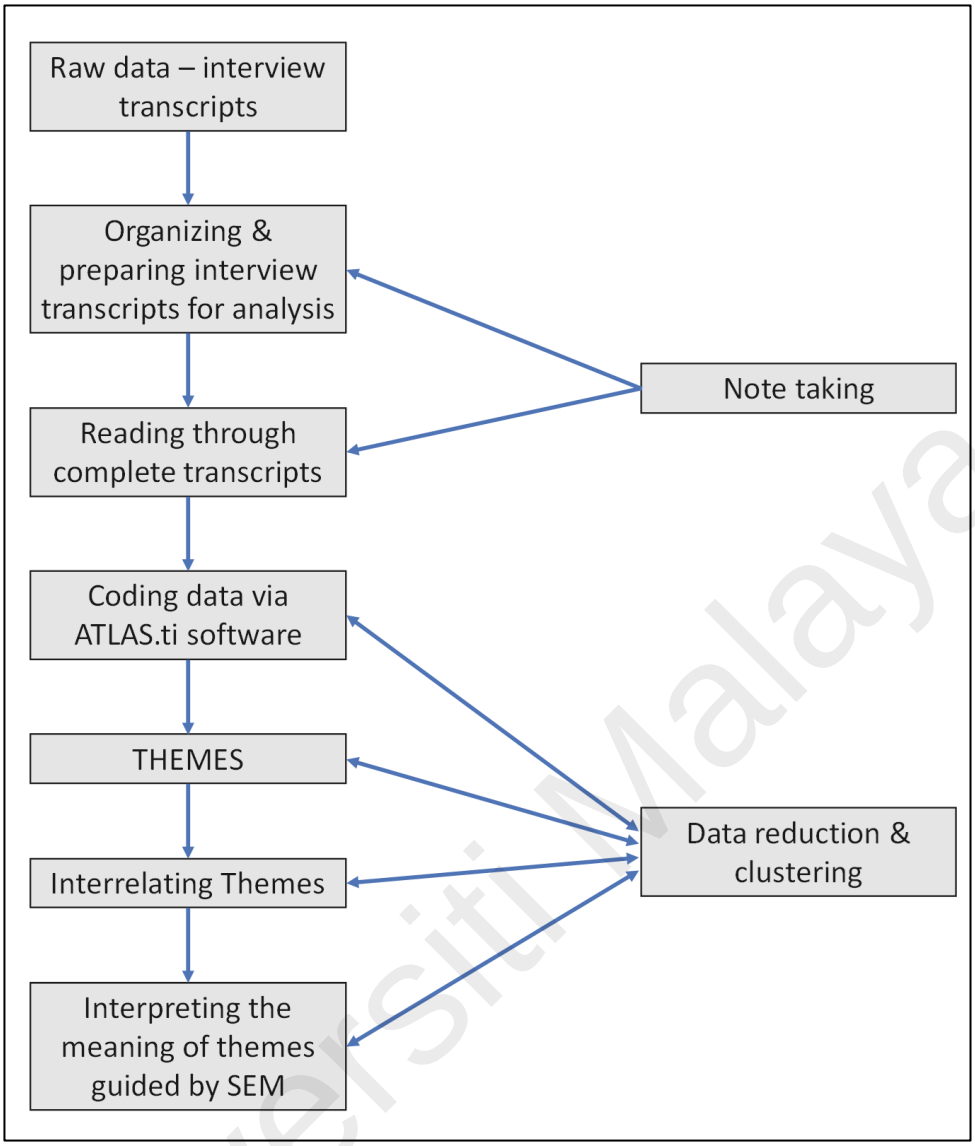


Figure 3.3: Seven step data analysis
Source: (Creswell, 2008)
SEM – Socio-Ecological Model

This efficient framework developed Creswell (2008) was adopted in the thematic analysis to identify patterns

1. **Familiarizing with the data** – involved transcribing verbatim the in-depth interviews with key opinion leaders into Microsoft Words, subsequently reading and re-reading the transcripts and noting down initial thoughts. Verbatim transcription is the most commonly used method of qualitative data collection to enhance the credibility and authenticity of the data (Polit & Beck, 2010). The

interviews for transcription were organized and prepared into AtlasTI. The audio recordings and transcripts of the interviews were stored in the laptop, which were passwords protected.

2. **Coding the data** – involved producing succinct codes for entire dataset so that important information relevant to the research question is highlighted and aggregated together. No pre-determined coding system was used, but instead, the codes and the themes were sourced directly from the dataset. AtlasTI software package was used to code and store the transcripts to ensure the proper storage and retrievability.
3. **Searching important themes** – involved examining the codes and aggregated all relevant codes into each preliminary theme. It was done by the development of sub-themes and themes through careful consideration of the underlying meanings, concepts and interpretation of the data (Sandelowski & Barroso, 2003) which was guided by the SEM model by Kumar (2018)
4. **Reviewing the themes** – involved modifying the particular themes by splitting, combining or discarding them accordingly to the dataset, which will answer the research question of ReTRAPP. A thematic map of analysis was produced to show the links and relationships between codes.
5. **Defining the themes** – involved refining the themes by detailed analysis of each theme to understand what each theme is about and how they interact with each other.
6. **Write up** – involved contextualizing the narrative of the complex data into a report to relate the analysis to the research question and the Kumar (2018) SEM to describe the barriers and solutions that influence renal transplantation process in Malaysia.

The emerging themes or patterns within data were identified with an inductive 'bottom-up' way method. An inductive approach recognizes the themes that were generated from the data via unrestricted open coding (Boyatzis, 1998) which was followed by the refining of the themes based on the six-phase framework by (Braun & Clarke, 2006). In this method in which the data were collected for a specific research subject, i.e. key opinion leaders in renal transplantation, the recognized themes are emergent because the researcher was examining the transcripts for unexpected codes that were not literal and descriptive in nature. Figure 3.4 shows the summary on how the qualitative component of ReTRAPP study was conducted.

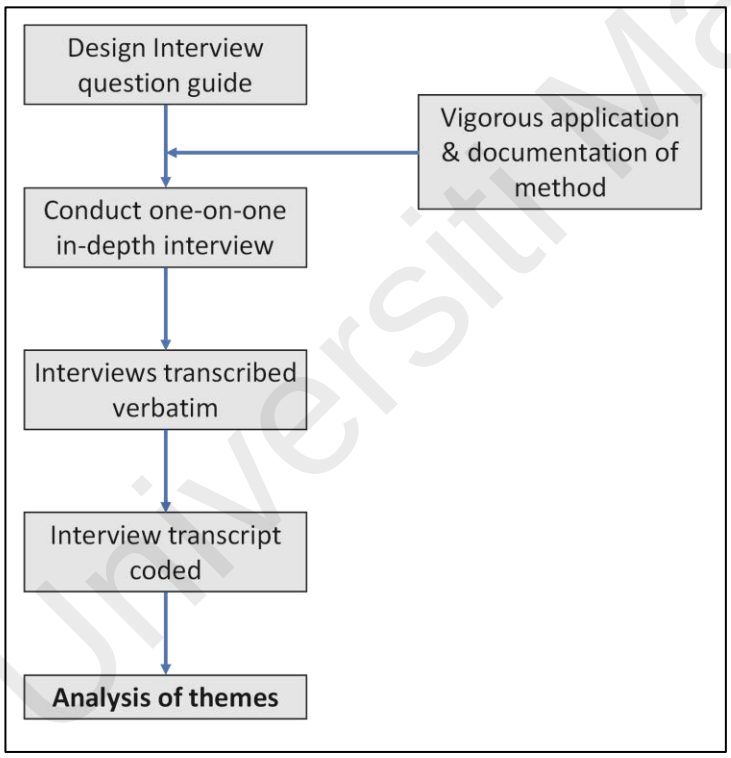


Figure 3.4: Steps of data collection for a one-on-one in-depth interview

3.3.8.1 Data Saturation

A total of eight key-informants were interviewed for the qualitative component of ReTRAPP study. The primary goal for the qualitative study is generally to reach data saturation with the interviews conducted. As such, a constant comparative method of analysis was employed by transcribing, analysing, and coding the interviews once it was conducted. When no further additional information was extracted from the subsequent interviews, it is considered that data saturation is reached. Table 3.4 indicates the number of new codes that were gleaned in each interview.

Table 3.4: Number of codes derived from key informant interviews

Interview	Gender	Number of New Codes
First	Male	74
Second	Female	38
Third	Male	12
Four	Female	2
Fifth	Male	9
Sixth	Male	1
Seventh	Female	0
Eighth	Male	0

In the case of the current study, the final two interviews did not produce any new coded data during analysis. Conducting further interviews would not be productive as it is unlikely that new information will be obtained, and the Researcher determined that data saturation was reached.

3.3.8.2 Reliability

The trustworthiness of the study findings depends on the transparency of the data collection and analysis processes to ensure the reliability of the qualitative study (Golafshani, 2003; Polit & Beck, 2010). Transparency in qualitative study refers to the

organized and systematic documentation of the methodology and the findings from the analysis. Therefore, the test of reliability in qualitative research depends on its consistency (Grossoehme, 2014). The findings mirrored the experiences and insight of the key-informants as reported in the in-depth interview transcripts rather than from pre-determined assumptions dictated by the Researcher (Shenton, 2004). Although the key-informants may share completely different viewpoints, the heterogeneity contributes to the wealth of knowledge on renal transplantation. Researcher regularly verified the accuracy of the information extracted from the key-informants in terms of form and context (Leung, 2015) by comparing with quantitative data whenever possible (Patton, 1999).

3.3.8.3 Credibility

Credibility essentially measures the link between the study's findings with reality to demonstrate the study's findings answer the research question (Thorne, 2011). The credibility of the findings and the trustworthiness of the findings is established by comparing what is known about renal transplantation, sometimes referred to as triangulation (Carter et al., 2014). According to Breitmayer, triangulation can be classified into

1. Triangulation of data methods
2. Triangulation of data source
3. Theoretical triangulation
4. Triangulation of investigator (Breitmayer, 1991)

For ReTRAPP study, two methods of triangulation were adopted. Firstly, for the part of the Researcher, evidence from a variety of data sources was collected; such as literature review of published studies on renal transplant, transplant law and policies and newspaper articles. On the other hand, key informant interviews were conducted with a pool of key opinion leaders from different fraternity and background to develop a holistic understanding of the renal transplantation system in Malaysia. Having more than one source of information often give more comprehensive data and insight into the topic of research (Carter et al., 2014).

Besides that, we critically explored the list of codes together and gave a different perspective adding breadth to the topic on renal transplantation. These discussions led to the modification and refinement of the themes which were finalized by consensus.

3.4 Association of Socioeconomic Status on Access to Renal Transplantation and Post-Transplant Survival

3.4.1 Study Design

A retrospective longitudinal cohort study design was used to investigate the access to and survival rate of renal transplantation in Malaysia. Data were extracted from the National Renal Registry between January 2002 and December 2011 on patients underwent renal transplantation with annual follow up till December 2016. Follow-up time was censored at 5-years to correspond with other studies conducted on the outcome of renal transplantation indicating the development of cardiovascular disease within 4 – 5 years (Bottomley & Harden, 2013; Israni et al., 2010; Jiang et al., 2013)[3].

The longitudinal observation approach was an appropriate method due to its capability to study the outcomes (access and survival rate) after the exposure (socioeconomic status); the ability to yield accurate incidence rates, values of relative risks, and other measures of association (Euser et al., 2009). The primary rationale of using the registry was because it is the only nationwide renal registry in Malaysia. By choosing this registry, it would be able to ensure that the target population was large enough to obtain precise estimates and to have a representative sample of adult RTRs in Malaysia.

[3] (Y. N. Lim et al., 2011) reported that 3 – 4 % of renal transplant recipients developed cardiovascular disease post transplantation and it was the most common cause of death for renal transplant recipients after infection.

3.4.2 Data Source

The Malaysian Dialysis and Transplant Registry (MDTR) is a spin-off from the Dialysis and Transplant Registry which was established by the Department of Nephrology of the Kuala Lumpur Hospital. Its primary function was to collect data from end-stage renal disease (ESRD) patients who are on renal replacement therapy (RRT).

The MDTR maintains a database of RTRs in Malaysia. The data is collected nationwide from all RRT providing centres regardless if they are governmental or private centres. The data is voluntarily collected from individual doctors, medical assistants and nurses who provided care for the patients on RRT in these centres.

The MDTR coordinated with the National Vital Registration System (*Jabatan Pendaftaran Negara*) to determine the mortality outcomes of RTRS who are lost to follow-up from these RRT providing centres. For the renal transplant portion of the registry, MDTR provide four forms for data collection

1. Renal Transplant Notification
2. Renal Transplant Outcome Notification
3. Renal Transplant Annual Return
4. Work-Related Rehabilitation and Quality of Life Assessment of Dialysis and Transplant Patients

Data were extracted from the Renal Transplant Notification form, Renal Transplant Outcome Notification form and Renal Transplant Annual Return form for data analysis (refer Appendix E, F and G).

The dataset was provided by the manager of the National Renal Registry. The manager de-identified the data by excluding all non-essential identifiable variables, such as name, identity card number, addresses from the original database of the registry. After excluding all the non-essential identifiable variables, the manager assigned a unique, number to each patient and could not be traced back to the specific patient. The key which linked the original identification to the random number identification was kept confidential by the manager. No patients were contacted for this study. The Researcher received the data in Microsoft Excel spreadsheets saved in a pen drive that was password protected only known to the manager and the Primary Researcher.

3.4.3 Sampling Procedures

The retrospective longitudinal cohort study of ReTRAPP study employed a universal sampling approach to all the renal transplant recipients (RTRs). They underwent renal transplantation between 1st January 2002 and 31st December 2011 enlisted in the Malaysian Dialysis and Transplant Registry (MDTR) of National Renal Registry, Malaysia. Subsequently, data were collected from the annual follow up of the RTRs till 31st December 2016. Figure 3.5 presents a flow chart of the process of RTRs exclusion from the total samples in the registry.

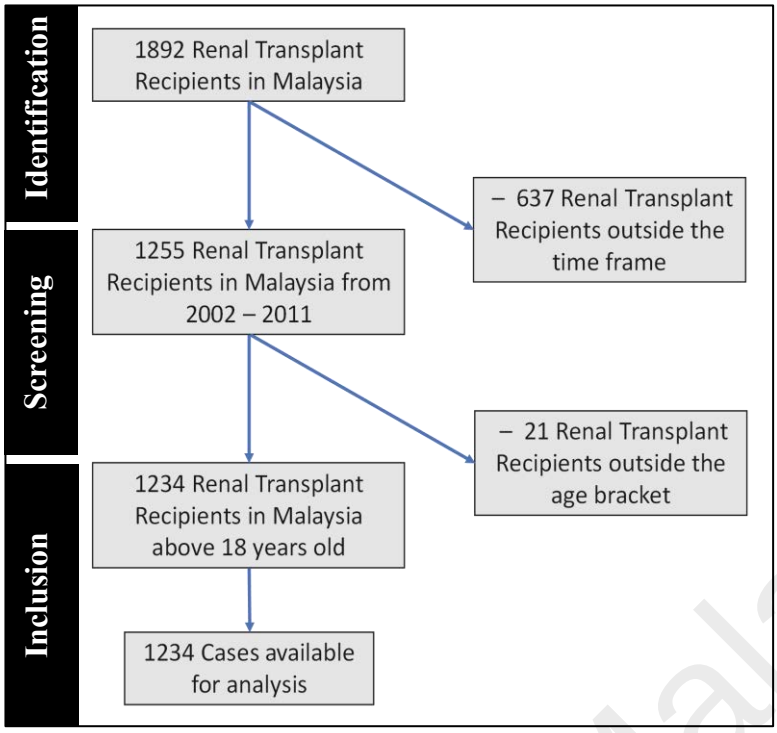


Figure 3.5: Flow chart of the study process for secondary data

3.4.4 Participants

The target population for the longitudinal observation study are ESRD patients who are RTRs in Malaysia. The retrospective longitudinal cohort study comprised of 1255 RTRs who had undergone renal transplantation from 2002 to 2011.

3.4.4.1 Inclusion and Exclusion Criteria

The 1255 RTRs who have undergone renal transplantation from 2002 to 2011 were screened based on the following criteria for eligibility into ReTRAPP study

1. Malaysian
2. Above 18 years old
3. Undergone renal only transplantation between 2002 and 2011

However, for the patients who have undergone renal transplantation more than once were excluded from the cohort. After carefully selecting the patients based on the criteria listed above, a total of 1234 RTRs were eligible to be included in the analysis.

3.4.4.2 Sample Size

To ensure that the number of patients extracted from the registry was sufficient, the sample size was calculated based on a similar study that was conducted in Malaysia (Bavanandan et al., 2015). PS: Power and Sample Size Calculation, Version 3.1.2, 2014, was used to calculate tests of power for sample size made available from the registry. PS: Power and Sample Size Calculation is a free, web-based, open-source software package for performing power calculation which covers the most commonly used study designs and is relatively easy to use (McCrum-Gardner, 2010)

Evaluation of the independent cohorts was performed using the log-rank test, a approached proposed by (Schoenfeld & Richter, 1982)., the hazard ratio of 5.0 and 4.5 for waiting time and survival rate for renal transplantation respectively was adopted for the calculation of the power of this study (Bavanandan et al., 2015). With a total of 1234 patients recruited over 10 years and followed up for five years, the number of participants was sufficient to detect an error of probability of 5% and provide a 100% power to the study (refer table 3.5)

Table 3.5: Determining the power of the study for secondary data

Objective	α	Power	R	m_1	A	F	m	N
2	0.05	**1.000**	*5.0*	12.5	10	5	1	**1234**
3	0.05	**1.000**	*4.5*	13.8	10	5	1	**1234**

α	Type I error probability
Power	Probability of correctly rejecting the null hypothesis
R	Hazard ratio (relative risk) of dialysis relative to renal transplantation – source (Bavanandan et al., 2015)
m_1	Median survival time on renal transplantation – source (Bavanandan et al., 2015)
A	Accrual time during which participants are recruited
F	Additional follow-up time after the end of the recruitment
m	Ratio of control to experimental patients
N	Number of participants =1234 from 2002 – 2011 (obtained from Malaysian Dialysis and Transplant Registry)

3.4.5 Specific Ethical Considerations

The data extracted from the registry was anonymised, but access to the original identifiers was retained securely by the manager. This component was based on the analysis of anonymised secondary data, individual patient's informed consent was deemed unnecessary because a full consent from the National Renal Registry was obtained. Only the city location was released with the dataset, to maintain the confidentiality of the renal transplant recipients. By using secondary data for analysis,

1. it maximizes the value of data collection done by registry
2. it reduces the burden on the participants
3. it ensures replicability of study findings and therefore, greater transparency of research procedures and integrity of research work.

The dataset was provided by the manager in the form of a spreadsheet in Microsoft Excel with password protection that only the Researcher would know. SPSS datasets do not have a password protection facility, so the SPSS file was held on a password-protected

laptop computer. The Researcher took extra precaution to ensure that reporting of the results of the study either by publishing a summary in medical journals, conferences or meeting will be done as a collective and no individual patient shall be identified in any publication or report of the study. The longitudinal cohort study fulfilled the following ethical criteria set by Morrow (2014) for the utilization of secondary data

1. Data must be anonymized before released to the Researcher
2. Consent of study subjects can be reasonably presumed
3. Results from research must not allow re-identifying participants
4. Use of the data must not result in any damage or distress to participants (Morrow et al., 2014)

3.4.6 Operational Definitions

Table 3.6: List of operational definitions for quantitative study (secondary data)

<table>
<tr><th>Terminology</th><th>Description</th></tr>
<tr><td>Medical Registry</td><td>An organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition or exposure and that serves one or more predetermined scientific, clinical or policy purposes (Gliklich et al., 2014).</td></tr>
<tr><td>Level of educational attainment</td><td>The highest educational attainment level of the renal transplant recipient. It can be classified according to the Department of Statistics Malaysia (Department of Statistics Malaysia, 2018a)
<table>
<tr><th>Education Attainment</th><th>Classification</th></tr>
<tr><td>Primary</td><td>• Primary 1
• Primary 2
• Primary 3
• Primary 4
• Primary 5
• Primary 6</td></tr>
<tr><td>Secondary</td><td>• Lower Secondary
o Form 1
o Form 2
o Form 3
• Upper Secondary
o Form 4
o Form 5</td></tr>
<tr><td>Tertiary</td><td>• Pre-University
o Form 6 (lower and upper)
• Certificate from College / Polytechnic / University
• Certificate in teaching/nursing /allied health
• Diploma
• Advanced diploma
• Bachelor’s degree
• Master’s degree
• Doctoral degree
• Post-doctoral fellowship</td></tr>
</table>
</td></tr>
</table>

"Continued"

Table 3.16: List of operational definitions for quantitative study (secondary data)

<table>
<tr><th>Terminology</th><th>Description</th></tr>
<tr><td>Kidney transplant centre</td><td>Refers to the hospital or medical centre that the renal transplantation surgery was performed. It can be performed in
<table>
<tr><th>Local</th><th>Countries Abroad</th></tr>
<tr><td>1. Kuala Lumpur Hospital</td><td>1. China</td></tr>
<tr><td>2. Selayang Hospital</td><td>2. India</td></tr>
<tr><td>3. University of Malaya Medical Centre</td><td>3. Pakistan</td></tr>
<tr><td>4. Universiti Kebangsaan Malaysia Medical Centre</td><td>4. Singapore</td></tr>
<tr><td>5. Prince Court Medical Centre</td><td>5. Sri Lanka</td></tr>
<tr><td>6. Subang Jaya Medical Centre</td><td>6. United Kingdom</td></tr>
<tr><td>7. Gleneagles Intan Hospital</td><td rowspan="2">7. Others</td></tr>
<tr><td>8. Selangor Medical Centre</td></tr>
</table>
</td></tr>
<tr><td>City and the state capital</td><td>The residence of RTRs will be categorized into major city (e.g. gazetted as city or are capital of each state) and others (e.g. includes all other cities, municipal status and district status).
<table>
<tr><th colspan="2">City status</th></tr>
<tr><td>1. Kuala Lumpur</td><td>8. Alor Setar</td></tr>
<tr><td>2. Petaling Jaya</td><td>9. Kota Bharu</td></tr>
<tr><td>3. Shah Alam</td><td>10. Kuala Terengganu</td></tr>
<tr><td>4. Ipoh</td><td>11. Kuching</td></tr>
<tr><td>5. Georgetown</td><td>12. Miri</td></tr>
<tr><td>6. Johor Bharu</td><td>13. Kota Kinabalu</td></tr>
<tr><td>7. Malacca</td><td></td></tr>
</table>
Source: (Department of Statistics Malaysia, 2010a)
<table>
<tr><th colspan="2">State Capital</th></tr>
<tr><td>1. Shah Alam</td><td>7. Alor Setar</td></tr>
<tr><td>2. Ipoh</td><td>8. Kota Bharu</td></tr>
<tr><td>3. Georgetown</td><td>9. Kuala Terengganu</td></tr>
<tr><td>4. Johor Bharu</td><td>10. Kuching</td></tr>
<tr><td>5. Malacca</td><td>11. Kangar</td></tr>
<tr><td>6. Seremban</td><td>12. Kota Kinabalu</td></tr>
</table>
</td></tr>
</table>

"Continued"

Table 3.16: List of operational definitions for quantitative study (secondary data)

<table>
<tr><th>Terminology</th><th>Description</th></tr>
<tr><td>Greater Kuala Lumpur definition (secondary data)</td><td>All transplant centres are in the Greater Kuala Lumpur. The renal transplant recipient's residence is concerning the transplant centre is within the Greater Kuala Lumpur or not.

<table>
<tr><th colspan="2">Greater Kuala Lumpur</th></tr>
<tr><td>1. Kuala Lumpur</td><td>7. Ampang Jaya</td></tr>
<tr><td>2. Petaling Jaya</td><td>8. Kajang</td></tr>
<tr><td>3. Shah Alam</td><td>9. Hulu Langat</td></tr>
<tr><td>4. Selayang</td><td>10. Petaling</td></tr>
<tr><td>5. Klang</td><td>11. Gombak</td></tr>
<tr><td>6. Subang Jaya</td><td>-</td></tr>
</table>
Source: (Gin, 2017)</td></tr>
<tr><td>Classification of occupation</td><td>Based on Malaysia Standard Classification of Occupations 2008 (MASCO) by (Ministry of Human Resources Malaysia, 2010) which was further grouped into categories (Department of Statistics Malaysia, 2018b)

<table>
<tr><th>Employment Category</th><th>Type of occupation</th></tr>
<tr><td rowspan="5">Employed</td><td>▪ Managers
▪ Professionals
▪ Technicians
▪ Associate Professors</td></tr>
<tr><td>▪ Clerical support workers
▪ Service and sales workers
▪ Skilled agriculture, forestry and fishery workers
▪ Craft and related trade workers
▪ Civil service (armed forces)</td></tr>
<tr><td>▪ Plant and machine operators
▪ Assemblers
▪ Elementary occupation</td></tr>
<tr><td>▪ Business owners
▪ Self-employed</td></tr>
<tr><td>Outside Workforce</td><td>▪ Housewives/homemakers
▪ Students
▪ Retiree/Pensioners</td></tr>
<tr><td>Unemployed</td><td>▪ Unemployed</td></tr>
</table></td></tr>
</table>

"Continued"

Table 3.16: List of operational definitions for quantitative study (secondary data)

Terminology	Description
Household income currency exchange	Household income from the National Renal Registry are classified following the conversion to United States Dollar (USD) (Bank Negara Malaysia, 2019) ▪ < RM 1000 (< USD 239) ▪ RM 1000 – RM 3000 (USD 239 – USD 717) ▪ > RM 3000 (> USD 717) Conversion rate, RM 1 = USD 0.239
Body Mass Index (BMI)	Body Mass Index which is defined as the body weight in kilogram divided by height, in meters squared. BMI is widely used in epidemiological studies to predict the risk for obesity-related morbidity and mortality in adults. The classification of BMI for Asian and Pacific populations was redefined because evidence has suggested that at a lower BMIs, there are increased risks of co-morbidities in for Asians. BMI classified based on the recommendation by (World Health Organization Expert Consultation, 2004) ▪ < 18.5 kg/m^2 ▪ 18.5 – 22.9 kg/m^2 ▪ 23.0 – 27.5 kg/m^2 ▪ > 27.5 kg/m^2

3.4.7 Outcomes Measured

3.4.7.1 Independent and Dependent Variables

Table 3.7: Independent and Dependent Variables for the retrospective longitudinal cohort study

Specific Objectives	Independent Variables	Dependent Variables
To examine the impact of socioeconomic factors on access to renal transplant	1. Educational attainment 2. Employment status 3. Household income	Duration of wait-listing before renal transplantation
To determine the effect of socioeconomic factors on the survival of renal transplant recipients	1. Educational attainment 2. Employment status 3. Household income	Duration of renal transplant recipient survival post-transplantation

3.4.7.2 Covariates

Table 3.8: Variables studied in ReTRAPP based on literature review

No	Category	Variables
1	Socio-demographic data (non-medical data)	1. **Age** (Akolekar et al., 2013; Dudley et al., 2009; Machado et al., 2011) 2. **Gender** (S Bayat et al., 2015; Couchoud et al., 2012; Machado et al., 2011) 3. **Ethnicity** (Hall et al., 2012; Joshi et al., 2013; Yeates et al., 2004) 4. **Marital status** (Bunzel & Laederach-Hofmann, 2000; Khattak et al., 2010; Naiman et al., 2007) 5. **Geographical location** (Axelrod et al., 2014; Mathur et al., 2010) 6. **Educational attainment**(Axelrod et al., 2010; Kihal-Talantikite et al., 2016; Schaeffner et al., 2008) 7. **Household income** (Axelrod et al., 2010; Kihal-Talantikite et al., 2016) 8. **Employment status** (Axelrod et al., 2010; Sahar Bayat et al., 2006; Kihal-Talantikite et al., 2016)
2	Data pre-transplantation (medical data)	1. **Transplant centre** (Axelrod et al., 2010) 2. **Donor type** (Gordon et al., 2010; Legendre et al., 2014) 3. **Duration of waiting time** (Meier-Kriesche et al., 2000) 4. **Smoking** (Akolekar et al., 2013; Arce et al., 2013; J. S. Gill et al., 2007) 5. **Body mass index (BMI)** (Sahar Bayat et al., 2006; J. S. Gill et al., 2014) 6. **Pre-transplant dialysis modality** (Akolekar et al., 2013; Machado et al., 2011) 7. **Comorbid conditions** a. **Diabetes mellitus** (Akolekar et al., 2013; Arce et al., 2013; J. S. Gill et al., 2007; Y. Zhang et al., 2017) b. **Hypertension** (Arce et al., 2013; J. S. Gill et al., 2007; Y. Zhang et al., 2017) c. **Coronary artery disease** (Akolekar et al., 2013; Arce et al., 2013; Marcello Tonelli et al., 2009; Y. Zhang et al., 2017) d. **Cerebrovascular accident** (Gordon et al., 2010; Jain et al., 2009) e. **Cancer** (Arce et al., 2013; Marcello Tonelli et al., 2009; Y. Zhang et al., 2017) 8. **Primary renal disease** (glomerulonephritis, diabetes mellitus, hypertension, obstructive uropathy, ADPKD, drug / toxic nephropathy, hereditary nephritis) (Dudley et al., 2009; Khattak et al., 2010; Lefort et al., 2016)

"Continued"

Table 3.8: Three categories of variables studied

No	Category	Variables
3	Data post-transplantation (medical data)	1. **Date of graft failure** 2. **Date of death** 3. **Duration of survival** 4. **Body mass index** (Lafranca et al., 2015; Nicoletto et al., 2014) 5. **Complication post-transplantation** a. **Diabetes mellitus** (Farrugia et al., 2014; Gordon et al., 2010; Nilakantan et al., 2016) b. **Coronary artery disease** (Axelrod et al., 2010) c. **Cerebrovascular disease** (Gordon et al., 2010; Jain et al., 2009) d. **History of malignancy** (Sahar Bayat et al., 2009)

3.4.8 Methods of Handling Missing Data

Retrospective registry-based data was used for this analysis. Demographic details, investigational results, and other vital information may be missing due to lack of availability, refusal to provide, or incorrect documentation.

A proper method of handling missing values was paramount because if missing data is improperly handled, it will distort the statistical analyses. The general assumption is that missing data differ in analytically important ways from data where values are present or complete. If the analyses only look at complete cases and exclude the cases with missing data, it would lead to (Kwak & Kim, 2017)

1. loss of statistical power
2. loss of information
3. lack of generalizability
4. remaining data set can introduce bias into estimates

Garson suggest that missing data are a form of measurement error (Garson, 2015). Therefore, the missing data may be bias towards the sample and attenuate effect sizes. Data imputation may reduce bias but also may introduce systematic regularities in the data arising from the prediction method. Based on the classification by (Kalton, 1983), missing data can be due to

1. **Subject non-response** or **unit non-response,** which happens when the renal transplant recipients (RTRs) fail to participate in the survey. It could be due to circumstantial reasons such as refusal to participate, too ill to participate, cannot participate because of language or hearing problems.
2. **Item non-response** which happens when the RTRs participates in the survey but fails to respond to one or more of the survey questions. This failure may occur because the RTRs refused to answer a question because of (Amahia, 2010)
    a. Fatigue with the instrument
    b. The sensitivity of the item
    c. Interruptions while taking the completing the form
    d. Information is unknown or not readily available
    e. In multi-stage data collection, the patient may be absent at one or more stages
    f. Loss of data during coding and storing

To produce a valid result by imputation, the missingness of the dataset has to be one of the followings

1. **Missing completely at random (MCAR) model** assumes that the missing data occurs entirely at random across the distribution. Therefore, the probability of missingness of a variable does not depend on the values of other variables that

are observed or unobserved (Roderick JA Little & Rubin, 2014). Data that are MCAR will produce an unbiased estimate with basic statistical analysis method (Hox, 1999).

2. **Missing at random (MAR) model** assumes the probability of missingness of a variable is systematically related to the observed but not the unobserved data (Roderick JA Little & Rubin, 2014). MAR is observed when the missing data is statistically significant when using Little's MCAR test. Data that are MAR will produce unbiased estimate if the estimation method used to render the missingness mechanism is ignorable (Hox, 1999).

Little's MCAR test uses the expectation-maximization (EM) algorithm to reads in the raw data, with missing values, and reads out a variance-covariance matrix and vector of means (Graham, 2009). The test was used to differentiate if the pattern of the missing data is missing completely at random (MCAR) or missing at random (MAR). By using IBM SPSS, the missing data is assumed to be MAR because the EM mean is significant ($p < 0.001$), and the **null hypothesis was rejected**. It indicates that the data are not missing completely at random, and there is some systematic bias whereby specific data that are not available may be due to item non-response.

One of the standard methods used previously to handle missing data was by the traditional approach of deletion. It consists of either listwise deletion (by deleting any case with missing values) or pairwise deletion (delete "pairs" with specific missing values after calculating covariance or coefficient from all available data between pair of variables) (Peugh & Enders, 2004). However, for ReTRAPP, the listwise deletion was not appropriate because the dataset did not fulfil the MCAR assumption, and therefore cause bias in the estimates of the values (Donner, 1982; Kang, 2013). The pairwise deletion was not considered because the covariances contain different sample sizes and

standard errors that will prevent any further analyses (J.-O. Kim & Curry, 1977; Peugh & Enders, 2004).

Mean imputation[4] used the mean value of a variable is a substitute for the missing value for that same variable in the dataset (Peugh & Enders, 2004). This approach for MCAR or MAR datasets will produce biased estimates of any values except the mean and cause the sample size to increase leading to an underestimate of the errors (Malhotra, 1987) and was excluded from handling missing data. For regression imputation[5], all cases are maintained by substituting the missing value with a predictive value estimated from other available information and maintains most of the data (Kang, 2013). However, this method was not appropriate because like mean imputation, the sample size will increase, and the standard error will reduce (Kang, 2013).

Another method explored to handle missing data was by using the missing-indicator method[6] involves the creation of an additional missing category for the exposure variable for cases with missing data and not impute the missing values. Although simple to implement, this approach will produce apparent biases if the variable is a vital confounder or the effect of interest even when data are MCAR (Greenland & Finkle, 1995; Knol et al., 2010). Furthermore, the missing-indicator method is appropriate for categorical exposure only. It is not suitable to be applied to the outcome variable; in the case of ReTRAPP, 23% missing data is found in the outcome variable (I. R. White & Carlin, 2010).

[4] Initial method adopted to handle missing data but was found to be ineffective in reducing bias

[5] Initial method adopted to handle missing data but was found to be ineffective in reducing bias

[6] Initial method adopted to handle missing data but was found to be ineffective in reducing bias

Multiple imputation was selected by Researcher to handle missing data in ReTRAPP's secondary dataset because it is the least bias method. Multiple imputation was proposed by Rubin to overcome the issue of single imputation that would not be able to account for the sampling variability of the actual value of the missing data. Multiple imputation substituting missing values with M ($M \geq 2$) plausible imputed values to create M complete datasets (Rubin, 2004). Bayesian approach was used in determining the value to be imputed by averaging the distribution of the missing values given by the observed value (Sterne et al., 2009). It corrects the disadvantage of simple imputation by replacing more than one possible imputed value to the missing data. The significant benefits of using multiple imputation as described by Rubin are as follows

1. complete data methods were used to analyse each complete dataset
2. allow estimated value to be unbiased
3. the uncertainty of the estimation of values in the missing data case to be estimated in a reasonable way
4. imputation model does not have to match the substantive model
5. imputed datasets can be used more than once, and can be used to fit a range of models congenial with the model of interest (Rubin, 2004)

Subsequently, the statistical analysis was performed separately on each complete dataset, and the final analysed results were combined between datasets by using the multiple imputation combining rules (Rubin, 2004). The imputed datasets were independent of any standard statistical methods used to analyse the datasets. Estimated associations in each of the imputed datasets differed because of the variation introduced in the imputation of the missing values, and they are only useful when averaged together to give overall estimated associations. By using Rubin's Rule to calculate the standard error estimates, the analysis of imputed datasets reflected the uncertainty for both intra-

and inter-imputation (Rubin, 2004). It is associated with the estimation of missing data even though the imputed values were not the actual values (Greenland & Finkle, 1995; Kang, 2013; Stuart et al., 2009).

3.4.10 Missing Data from the Renal Transplant Registry

Table 3.9 shows a summary of the frequency table for variables selected from secondary data for analysis.

Table 3.9: Frequency table for variables from secondary data

Variable	Total (N)	Cases, n (%)	
		Valid	Missing
Socio-demographics			
Age	1234	1234 (100)	0
Gender	1234	1234 (100)	0
Educational Attainment	1234	1177 (95.4)	57 (4.6)
Household Income	1234	1140 (92.4)	94 (7.6)
Employment Status	1234	919 (74.5)	315 (25.5)
Ethnicity	1234	1226 (99.4)	8 (0.6)
Geographical Location	1234	1149 (93.1)	85 (6.9)
Medical characteristics			
Dialysis Modalities	1234	941 (76.3)	293 (23.7)
Smoking	1234	921 (74.6)	313 (25.4)
Waiting Time	1234	946 (76.7)	288 (23.3)
Transplant Centre	1234	1234 (100)	0
Pre-Transplant BMI	1234	1025 (83.1)	209 (16.9)
Post-Transplant BMI	1234	1111 (90.0)	123 (10.0)
Donor Type	1234	1218 (98.7)	16 (1.3)
Primary Disease	1234	1178 (95.5)	56 (4.5)
Comorbid Disease			
Diabetes Mellitus	1234	941 (76.3)	293 (23.7)
Hypertension	1234	941 (76.3)	293 (23.7)
Cancer	1234	941 (76.3)	293 (23.7)
Coronary Heart Disease	1234	958 (77.6)	276 (22.4)
Cerebrovascular Disease	1234	958 (77.6)	276 (22.4)
Post-Transplant Complication			
Diabetes Mellitus	1234	1234 (100)	0
Coronary Artery Disease	1234	1234 (100)	0
Cerebrovascular Disease	1234	1234 (100)	0
Cancer	1234	1234 (100)	0
Survival	1234	1234 (100)	0

3.4.11 Statistical Method

Missing data were addressed using multiple imputation for the secondary data obtained from the National Renal Registry using International Business Machines (IBM) Statistical Package for the Social Sciences (SPSS), version 22. The Markov Chain Monte Carlo (MCMC) multiple imputation method was employed (Schafer, 1999). Multiple imputation using Predictive Mean Matching (PMM) was performed because of its robustness in imputing the missing data with an observed value similar to the predicted value instead of an assumed model for the distribution (Roderick JA Little, 1988; T. P. Morris et al., 2014). PMM preserves the data distributions and imputes only non-negative values when the data consist of non-negative values. It is the only approach that ensures that the original data distribution is maintained (Vink et al., 2014). From figure 3.6, the number of missing cases was estimated at around 50% in the dataset. Hence, 50 imputations of the dataset with a 20 iteration per imputation totalling 1000 was performed (Bodner, 2008).

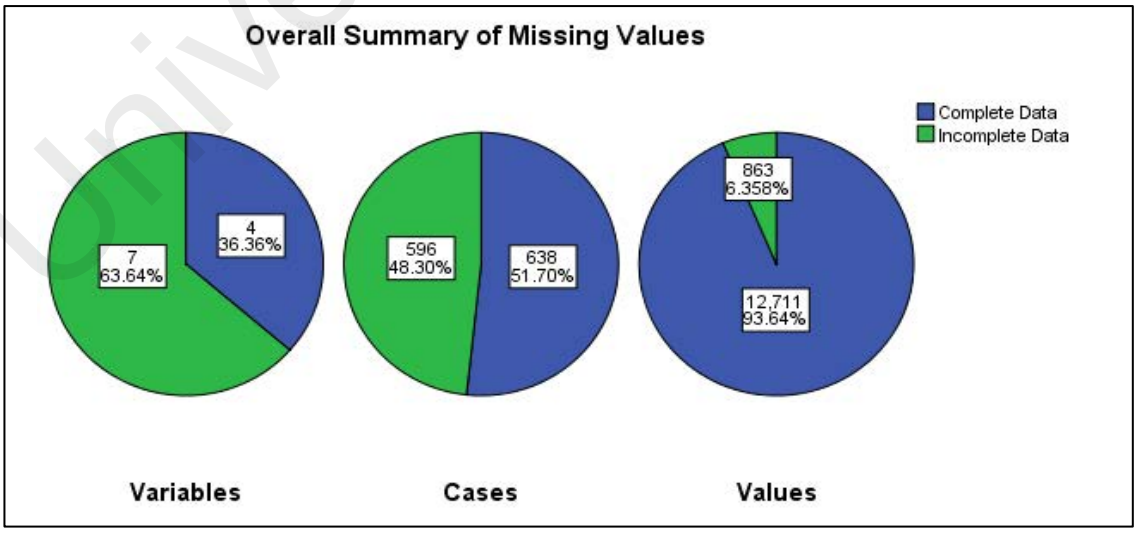


Figure 3.6: Percentage of missing cases in the dataset from the National Renal Registry

The statistical analyses were conducted using International Business Machines (IBM) Statistical Package for the Social Sciences (SPSS), version 22. Data cleaning on the secondary data was conducted through range checking and logical checking. Variables with impossible values were deleted to limit the impact of outliers. While for the continuous variables, variation beyond the recommended range could be possible, and the data is left unaltered. Descriptive statistics were used to describe renal transplant recipients' characteristics. Continuous variables were described using means and standard deviations, and categorical variables were described using frequencies and percentages. Means and medians were calculated as appropriate for age, BMI pre-transplant, BMI post-transplant, waiting time and the duration of survival post-transplant. Association between continuous variables was calculated using analysis of variance (ANOVA) to compare, and the association between categorical variables was calculated using chi-square test.

The association between access to renal transplantation with socioeconomic status (SES) of renal transplant recipients (RTRs) was determined with Cox proportional hazards by modelling time to transplantation from diagnosis of ESRD. SES was entered into the model independently as educational attainment, household income, and employment status. These regression models adjusted for confounding by controlling age (years), gender, ethnicity (Malay, Chinese, Indian, and Others), and geographical location (City/Outside City). Confounders were include based on epidemiologic plausibility and fulfilled the following (Rothman et al., 2008)

- associated with the exposure
- independently associated with the outcome
- not in the causal pathway between exposure and outcome.

Associations were reported as hazard ratios with 95% confidence interval (CI). A two-sided p-value of <0.05 was considered statistically significant. A trend test was used to assess a dose-response association. This trend test was performed by entering the SES variable in its ordinal scale as a continuous covariate in the analysis and checking for statistical significance.

Cox proportional hazards was also used to model the association between SES and survival time following renal transplantation. This model accounted for death by censoring it. SES was entered into the model either as educational attainment, household income, or employment status. These regression models adjusted for confounding by controlling age (years), gender, ethnicity (Malay, Chinese, Indian, and Others), and geographical location (City/Outside City). Associations were reported as hazard ratios (HR) with 95% confidence interval (CI). A two-sided p-value of <0.05 was considered statistically significant. A trend test was used to assess a dose-response association. This trend test was performed by entering the SES variable in its ordinal scale as a continuous covariate in the analysis and checking for statistical significance.

The interpretation of the hazard ratio can be difficult when used to access the duration of waiting-time for transplantation as an outcome. It is because a lower waiting-time to transplantation is a desirable event. Therefore, for a favourable outcome such as waiting-time to transplantation, a higher hazard ration is desirable

$$\text{Hazard ratio} = \frac{\text{hazard of transplant } (x=1)}{\text{Hazard of transplant } (x=0)}$$

Hazard ratio >1 is favourable

Hazard ratio <1 is unfavourable

3.5 Association of Socioeconomic Status on Post-Transplantation Quality of Life and Financial Burden

3.5.1 Study Design

A multi-centre cross-sectional study design was conducted between February 2018 and June 2018 to evaluate the association of socioeconomic status on post-transplantation quality of life and financial burden in renal transplant recipients (RTRs).

A cross-sectional approach is often hypothesis-generating and lacks temporality to determine a causal effect, but makes it possible to answer a research question quickly (Mann, 2003). However, a comprehensive understanding of the outcomes of the renal transplant recipients may allow for conclusions to be drawn about the quality of life and financial burden on the population of renal transplant recipients in Malaysia. Inference can also be made about possible relationships between socioeconomic status on these outcomes.

3.5.2 Setting

The Greater Kuala Lumpur is the most industrialized and most densely populated region in Malaysia. It is centred in Kuala Lumpur and extends to Rawang (northwest), Semenyih (southeast) and Klang (southwest) forming a triangular area (Gin, 2017). It is also the base where the financial and administrative capitals of Malaysia are located. According to the Department of Statistics Malaysia (2010), the total population in Greater Kuala Lumpur was estimated to be at six million people (Department of Statistics Malaysia, 2010b).

Greater Kuala Lumpur was selected as the study location because all renal transplant centres; Kuala Lumpur Hospital, Selayang Hospital, University of Malaya Medical Centre and Prince Court Medical Centre are located within the Greater Kuala Lumpur area. Within this study location, a total of six hospitals provide post-transplantation care to renal transplant recipients, as shown in Figure 3.7.

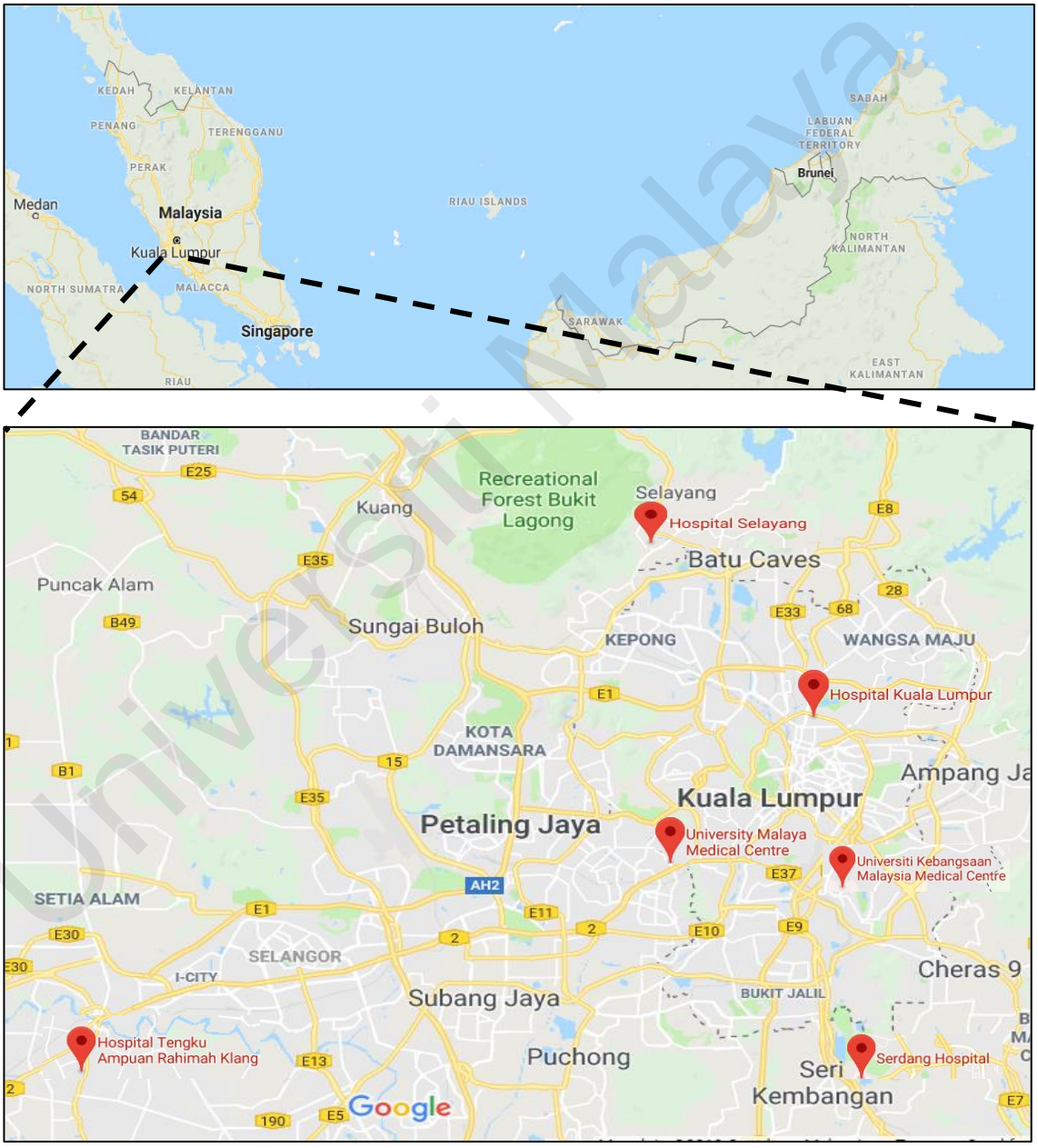


Figure 3.7: Map of Greater Kuala Lumpur showing the six sites for data collection (insert – map of Malaysia)
Source: (Google Maps, 2018)

3.5.3 Sampling Procedure

Ngu estimated 1892 renal transplant recipients (RTRs) in Malaysia as of 31st October 2017 (Ngu, 2018). From that figure, a total of 885 RTRs are under the care of the six hospitals mentioned earlier as of December 2018. Table 3.10 tabulates the number of RTRs for each government hospital in the Greater Kuala Lumpur with nephrology service.

Table 3.10: Number of kidney transplant recipients by hospital

No	Hospital	Number of Kidney Transplant Recipient
1	Kuala Lumpur Hospital	404
2	Selayang Hospital	149
3	Serdang Hospital	47
4	Tengku Ampuan Rahimah Hospital, Klang	46
5	University Malaya Medical Centre (UMMC)	189
6	University Kebangsaan Malaysia Medical Centre (UKMMC)	50
	Total	**885**

* Total number of RTRs as of 31st December 2017 (obtained from Malaysian Dialysis and Transplant Registry – MDTR)

In ReTRAPP's multi-centre cross-sectional study, universal sampling was applied to recruit participants at the nephrology out-patient clinic in the hospitals listed for their routine follow up appointment. The patients were briefed regarding ReTRAPP and were invited to participate in the study. After obtaining consent, the participants were invited to answer the self-administered survey while they wait in the out-patient clinic. The Researcher remains at the study site after distributing the survey to allow patients who had any queries or uncertainty regarding the questions asked. The primary data collection was predominantly conducted by the Researcher who developed and validated the

instrument. It would limit the inconsistency of non-self-completion by some of the participants if different interviewers were used.

Some of the participants required interviewer-assisted administration of the survey. The reason for the assistance is mainly due to sensory impairment (e.g. poor eye-sight or elderly persons who did not have their reading glasses with them at the time of administration) or literacy barrier (e.g. unable to comprehend the text of the survey fully). There were about 20 ESRD patients (slightly above 5% of total participants) who required interviewer-assisted administration in completing the survey. If assistance was not provided, the self-administration of the survey would have resulted in the participants unwilling to participate in leading to non-response. Bowling argued that a non-response bias might occur because the participants may differ from non-participants in their characteristics, which affects the precision (reliability) of the study's population estimates and weakening the external validity (generalizability) (Bowling, 2005).

There are many studies conducted that showed the heterogeneous effect of administering different mode of survey administration. However, a large cohort study that was conducted with 23,000 participants by (Puhan et al., 2011), demonstrated that there was no significant difference between the different approaches of survey administration which was repeated over time. The interviewer-assisted administration would lead to a "social desirability bias" whereby the participants would answer sensitive questions (e.g. drug consumption or sexual behaviour) based on societal norms or expectation to avoid being labelled as deviant (Bowling, 2005; Hoebel et al., 2014). Nonetheless, the ReTRAPP survey administered did not contain any sensitive question and therefore, would minimize the social-desirability bias. To further reduce this bias, the Researcher would reassure the participants that their confidentiality and anonymity would be maintained at all time.

The time frame for data collections was from February 2018 – May 2018 at all study sites except the University of Malaya Medical Centre (UMMC). Data collection at UMMC was extended till June 2018 because the outpatient clinic at Tengku Ampuan Rahimah Hospital, Klang ran concurrently with UMMC. Therefore, data collection for UMMC was extended for another month to overcome this logistical problem.

Each outpatient clinic of the hospital only operates once a week. During the data collection period, there were occasions when data collection was not conducted because public holidays fall on the clinic days or specific periods the outpatient clinics were rescheduled to accommodate the professional examination of clinical specialities in the hospital. Furthermore, there were certain days that the outpatient clinic visits were cancelled to accommodate for the key informant interviews. As a result, the number of clinic visits by the Researcher did not account for the actual number of outpatient clinic scheduled for the duration of the data collection. Figure 3.8 provides an overview of the process of primary data collection in 6 hospitals in Greater Kuala Lumpur.

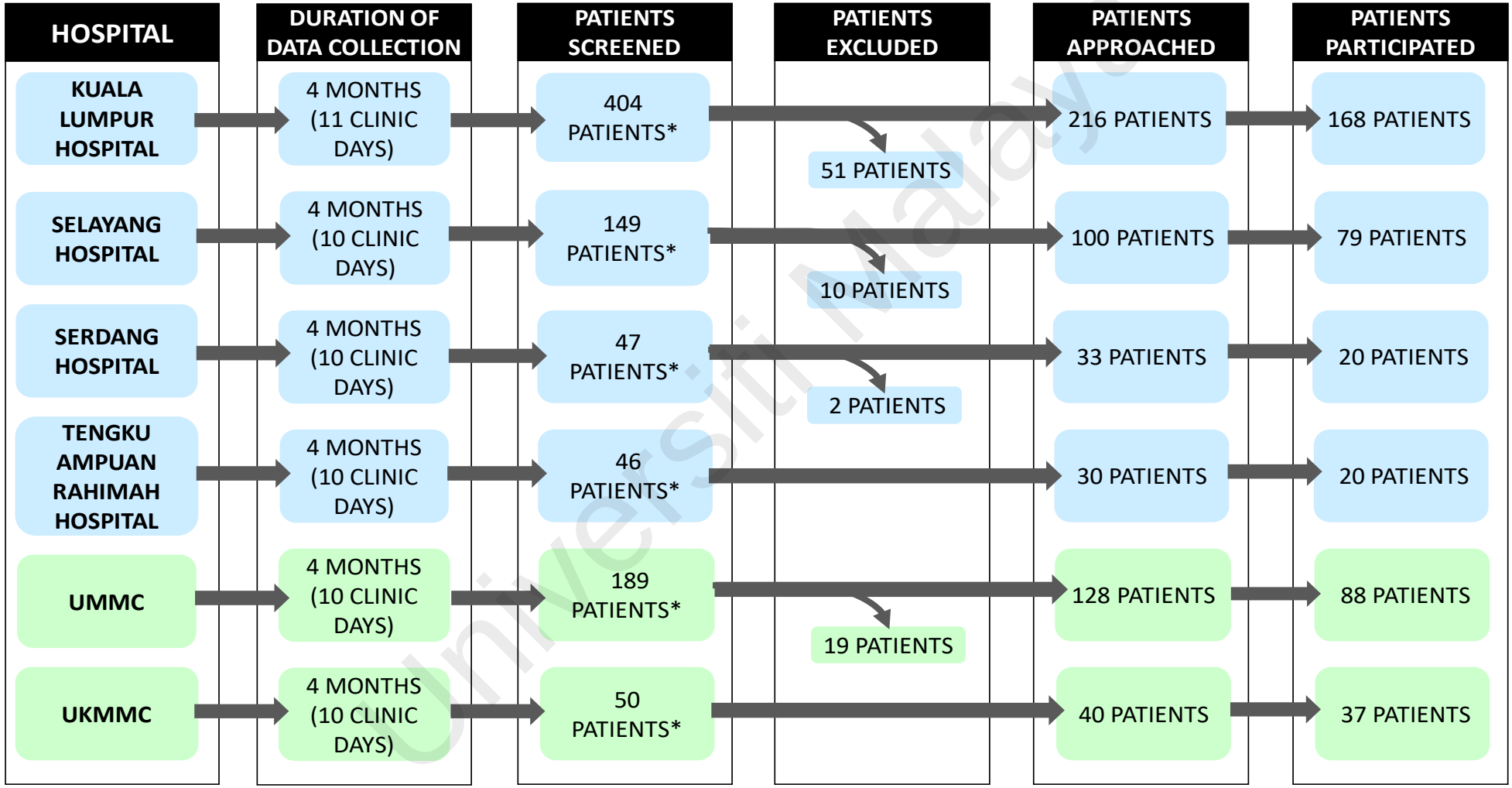


Figure 3.8: Flow chart of primary data collection for ReTRAPP

*Number of patients as of December 2017 (figures obtained from MDTR)

UMMC, University of Malaya Medical Centre; UKMMC, Universiti Kebangsaan Malaysia Medical Centre

Blue, Ministry of Health Hospitals; Green, Ministry of Education Hospitals

3.5.4 Participants

3.5.4.1 Inclusion and Exclusion Criteria

RTRs who were under the medical follow up of the six hospitals across the Greater Kuala Lumpur area were screened and recruited for the survey. These RTRs must fulfil the following criteria for eligibility of participation

1. Participant must be a renal transplant recipient
2. Male or female participant above 18 years old
3. Participant must be a Malaysian nationality
4. Participant must be able to read or understand English, Malay or Chinese
5. Participant must be able to provide consent to participate in ReTRAPP's survey

While some exclusion criteria were defined as follows

1. Renal transplant recipient who is diagnosed to have graft failure and to undergo dialysis
2. Renal transplant recipient who is diagnosed with an acute rejection of organ
3. Participant who has undergone renal transplantation less than six months ago[7]

[7] (R. J. Baker et al., 2017) recommended that uncomplicated RTRs be reviewed based on the following frequency

- 2–3 times weekly for the first month after transplantation
- 1–2 times weekly for months 2–3
- Every 2–4 weeks for months 4–6
- Every 4–6 weeks for months 6–12
- 3–6 monthly thereafter

At 6 months post-transplant, the follow up visits would be more stable (once monthly) which will provide a more accurate estimate of Quality of Life and financial burden of the RTRSs.

3.5.4.2 Sample Size

To the knowledge of the Researcher, there were no previous studies conducted using similar study instruments and outcome in Malaysia's context. Two sample sizes were calculated, and the bigger sample size was used for the cross-sectional study.

The first method would be to use G*Power to calculate the appropriate sample size. G*Power is a statistical software that is commonly used in medical and social behavioural studies as a stand-alone power analysis program for statistical testing (Faul et al., 2007). G*Power Software (Version 3.1.9.2) was used to calculate tests of power for sample size estimation. Junchotikul's value of effect size (r) was used to determine the sample size because the study used the same study instrument and study outcome (Junchotikul et al., 2015). From this study that was conducted in Thailand, the education variable was analysed for the post-renal transplantation patients' quality of life which yield a value of 0.194 (Junchotikul et al., 2015). A linear multiple regression analysis was completed to compare the level of education of RTRs to the quality of life of each RTRs. An a priori power analysis was computed to establish the required sample size, given α, power, and effect size. With a power of 0.80 (1-β error probability) and alpha of error probability of 0.05, the resulting sample size was calculated to be 149 RTRs. The non-response rate of participants is Considered, and therefore a total of 180 participants would be required[8].

The second method would be to use OpenEpi to calculate the sample size using proportions. OpenEpi is a free, web-based, open-source, operating system-independent series of epidemiologic and statistical tools that were designed for use in public health

[8] (Fincham, 2008) proposed that the response rate was between 60-80%. For ReTRAPP, a non-response rate of 30% was adopted from Fincham (2008).

and medicine (Sullivan et al., 2009). OpenEpi, Version 3.1, Open Source Epidemiologic Statistics for Public Health was used to calculate tests of power for sample size estimation. As mentioned, no previous research was conducted in Malaysia with a similar study instrument and outcome. Hence, a conservative solution is substituting the prevalence of quality of life and financial burden of RTRs with p=0.5 (Hajian-Tilaki, 2011). Assuming that the proportion is 50%, with an 80% power to detect this difference at the 5% significance level would provide a total sample size that was approximately 269 participants. Using a non-response rate of 30% (Fincham, 2008), the total sample size required was 350 participants.

A sample size of 350 renal transplant recipients was finalized for ReTRAPP in the multi-centre cross-sectional study by adopting the larger sample size calculation with a target of alpha error of 0.05 and a power of 0.80.

3.5.5 Specific Ethical Considerations

The primary mode of data collection for ReTRAPP's multi-centre cross-sectional study was implemented through a survey. Kelly et al. suggested that the most important ethical consideration when conducting a survey is the informed consent and the confidentiality of the participants (Kelley et al., 2003). ReTRAPP study was conducted following the Declaration of Helsinki and the Malaysian Good Clinical Practice guidelines on research ethics regarding informed consent. Each eligible participant that were approached in the out-patient clinic was informed by the Researcher regarding

1. the nature of the study
2. the benefits of participating in the study

3. that participation in the study is voluntary, and non-participation would not affect their treatment
4. information on how to contact the Researcher and the ethics committee for additional information about the study and their rights

Participants were informed during the informed consent process that they have the option of leaving questions that made them uncomfortable blank or of ending the survey at any time. The surveys were conducted in the outpatient clinics of the study sites, and the survey was self-administered without collecting any identifiable details. Therefore, confidentiality was ensured during the conduct of the survey and the collection of the survey forms.

3.5.6 Data collection

Based on the calculated sample size for the multi-centre cross-sectional survey, a total of 350 participants were required from all six locations of selected study sites. The ReTRAPP study was informed to respective Hospital Directors and Head of Nephrology Department for approval to survey their facilities. Once approval was obtained, the Researcher coordinated with the nephrology department to facilitate the administration of the survey during the out-patient clinic scheduled for the renal transplant recipients. The survey forms were distributed to all RTRs who were present for a routine medical follow-up appointment in the out-patient clinic.

The Researcher actively engaged the RTRs at the out-patient specialist clinics to participate, numerous strategies were implemented to improve the response rate of the participants. The average response rate of the survey from all six hospitals was at 74.7%.

Methods employed by Researcher to maintain contact with the study sample

1. engaging nurses and doctors from the out-patient clinics to inform RTRs about the study
2. Researcher was stationed in the out-patient clinic during the whole clinic period for RTRs to build rapport
3. enlist nurses based in the out-patient clinics to recruit for participants.

3.5.7 Operational Definitions

Table 3.11: List of operational definitions for primary data from the self-administered survey

<table>
<tr><th>Terminology</th><th>Description</th></tr>
<tr><td>Socioeconomic status</td><td>A composite measure that frequently incorporates economic, social, and employment status. The economic status is measured by income, while the social status is measured by education, and employment status is measured by occupation. Each status is considered an independent indicator that is typically linked but does not overlap (Adler et al., 1994).</td></tr>
<tr><td>Greater Kuala Lumpur definition</td><td>All transplant centres are in the Greater Kuala Lumpur. The renal transplant recipient’s residence is concerning the transplant centre within the Greater Kuala Lumpur or not.
<table>
<tr><th colspan="2">Greater Kuala Lumpur</th></tr>
<tr><td>1. Kuala Lumpur</td><td>7. Ampang Jaya</td></tr>
<tr><td>2. Petaling Jaya</td><td>8. Kajang</td></tr>
<tr><td>3. Shah Alam</td><td>9. Hulu Langat</td></tr>
<tr><td>4. Selayang</td><td>10. Petaling</td></tr>
<tr><td>5. Klang</td><td>11. Gombak</td></tr>
<tr><td>6. Subang Jaya</td><td></td></tr>
</table>
Source: (Gin, 2017)</td></tr>
</table>

"Continued"

Table 3.11: List of operational definitions for primary data from the self-administered survey

<table>
<tr><th>Terminology</th><th>Description</th></tr>
<tr><td>Level of educational attainment</td><td>Refers to the highest educational attainment of the renal transplant recipient based on Department of Statistics Malaysia (Department of Statistics Malaysia, 2018a)
<table>
<tr><th>Educational Attainment</th><th>Classification</th></tr>
<tr><td>Primary</td><td>▪ Primary 1
▪ Primary 2
▪ Primary 3
▪ Primary 4
▪ Primary 5
▪ Primary 6</td></tr>
<tr><td>Secondary</td><td>▪ Lower Secondary
o Form 1
o Form 2
o Form 3
▪ Upper Secondary
o Form 4
o Form 5</td></tr>
<tr><td>Tertiary</td><td>▪ Pre-University
o Form 6 (lower & upper)
o Matriculation
▪ A-Level Certificate from College / Polytechnic / University
▪ Certificate in teaching/nursing /allied health
▪ Diploma
▪ Advanced diploma
▪ Bachelor's degree
▪ Master's degree
▪ Doctoral degree
▪ Post-doctoral fellowship</td></tr>
</table></td></tr>
<tr><td>Multi-morbidity</td><td>Coexistence of two or more chronic conditions, where each must be a non-communicable disease (NCD Risk Factor Collaboration), a mental health disorder, or an infectious disease of extended duration (The Lancet, 2018). Patients with multiple conditions are more vulnerable to diseases and are more susceptible to infections (Mercer et al., 2016).</td></tr>
</table>

"Continued"

Table 3.11: List of operational definitions for primary data from the self-administered survey

<table>
<tr><th>Terminology</th><th>Description</th></tr>
<tr><td>Kidney transplant centre</td><td>Refers to the hospital or medical centre that the renal transplantation was performed. It can be performed in
<table>
<tr><th>Local</th><th>Countries Abroad</th></tr>
<tr><td>1. Kuala Lumpur Hospital</td><td>1. China</td></tr>
<tr><td>2. Selayang Hospital</td><td>2. India</td></tr>
<tr><td>3. University of Malaya Medical Centre</td><td>3. Pakistan</td></tr>
<tr><td>4. Universiti Kebangsaan Malaysia Medical Centre</td><td>4. Sri Lanka</td></tr>
<tr><td>5. Prince Court Medical Centre</td><td>5. Singapore</td></tr>
<tr><td></td><td>6. Others</td></tr>
</table>
</td></tr>
<tr><td>Classification of employment status</td><td>Based on studies by (Danuser et al., 2017; Parajuli et al., 2016; Tzvetanov et al., 2014) that were conducted in different countries, majority of the RTRSs who were unemployed pre-transplant will generally continue to be unemployed post-transplant. Therefore, ReTRAPP will identify the post-transplantation employment status of RTRSs based on the categories listed (Mikucka, 2016; Ministry of Health Malaysia, 2015)
<table>
<tr><th colspan="2">Employment Status</th></tr>
<tr><td>1. Full-time employment (Permanent / Contract)
2. Part-time employment
3. Self-employed</td><td>Employed</td></tr>
<tr><td>4. Homemaker
5. Student
6. Retiree / Pensioner</td><td>Outside Workforce</td></tr>
<tr><td>7. Unemployed</td><td>Unemployed</td></tr>
</table>
Source: (Department of Statistics Malaysia, 2018b)

The International Labour Organization reported that 70% of Malaysia's workforce was of non-standard employment which includes a high number of temporary employment like many Asian countries (International Labour Organization, 2016).</td></tr>
</table>

"Continued"

Table 3.11: List of operational definitions for primary data from the self-administered survey

Terminology	Description
Quality of life	The individual's perception of their position in life in the context of the culture and value systems in which they live and concerning their goals, expectations, standards and concerns (WHOQOL Group, 1995).
Financial burden (catastrophic health expenditure) for renal transplant recipients	Healthcare expenditure on post-renal transplantation management using out of pocket health expenditure spending exceeding 10% of household income was considered to be catastrophic, as it can potentially disrupt household living standards (Arsenijevic et al., 2016; Limwattananon et al., 2007; Loganathan et al., 2015; O'donnell et al., 2008; Raban et al., 2013).
Out-of-pocket health expenditure	The sum of direct medical expenditures on healthcare paid by RTRs themselves in the month preceding the survey.
Direct medical expenditure	Payment for hospital outpatient fees, medicines, admission or registration fees, physician/consultation fees, diagnostic test fees, and any other associated medical supplies.
Direct non-medical expenditure	Payment for transportation, lodging, tips and food.
Total medical expenditure	Sum of direct medical expenditure and direct non-medical expenditure
Personal income	The amount of money received monthly by the renal transplant recipient in exchange for labour or services (salary), pension, allowance, rent, from the sale of goods or property, or as a profit from investments.
Estimated household income	The amount of money received monthly by the renal transplant recipient and his/her family in exchange for labour or services (salary), pension, allowance, rent, from the sale of goods or property, or as a profit from investments.
Household gross income group and exchange rate	Below 40 = < RM 4360 (< USD 1042.04) Middle 40 = RM 4360 – RM 9619 (USD 1042.04 – USD 2298.94) Top 20 = > RM 9619 (> USD 2298.94) Classification by (Department of Statistics Malaysia, 2016; Khazanah Research Institute, 2018). Conversion rate of household income to the United States Dollar (USD) by (Bank Negara Malaysia, 2019) *Conversion rate, RM 1 = USD 0.239*

"Continued"

Table 3.11: List of operational definitions for primary data from the self-administered survey

Terminology	Description
Source of financing for medical expenses as a renal transplant recipient	Refers to payment of healthcare expenditure by renal transplant recipient and his/her family (Yu et al., 2008) 1. Out-of-pocket Payment (Leive & Xu, 2008) a. Current income b. Savings c. Sales of assets d. Money borrowed e. Others (e.g. unemployed family member begin to work to finance healthcare) f. Reducing household spending (Mondal et al., 2010) 2. Private financing a. Private healthcare insurance b. Employee insurance c. Employee Provident Fund (EPF) d. Non-governmental organizations 3. Public financing a. Free healthcare as a civil servant b. Community welfare department c. Zakat (Islamic social welfare system) d. Baitulmal (public institution and trustee group that handles Islamic finances) (Possumah & Ismail, 2012) 4. Others
Estimated total household expenditure	Refers to the essential household expenditure survey of Malaysia by (Bank Negara Malaysia, 2016) 1. Food and non-alcoholic beverages 2. Clothing and footwear 3. Health 4. Education 5. Housing, water, electricity, gas and other 6. Transport 7. Communication 8. Furnishings, household equipment and routine household maintenance 9. Recreation services and culture 10. Restaurants and hotels 11. Miscellaneous goods and services

"Continued"

Table 3.11: List of operational definitions for primary data from the self-administered survey

<table>
<tr><th>Terminology</th><th>Description</th></tr>
<tr><td>Hospital coding (visit site)</td><td>Hospitals designated for data collection are provided with a code for the multi-centre cross-sectional survey

<table><tr><th>Hospital</th><th>Code</th></tr><tr><td>Tengku Ampuan Afzan Hospital, Kuantan</td><td>0</td></tr><tr><td>Kuala Lumpur Hospital</td><td>1</td></tr><tr><td>UMMC</td><td>2</td></tr><tr><td>Selayang Hospital</td><td>3</td></tr><tr><td>UKMMC</td><td>4</td></tr><tr><td>Serdang Hospital</td><td>5</td></tr><tr><td>Tengku Ampuan Rahimah Hospital, Klang</td><td>6</td></tr></table></td></tr>
<tr><td>Subject number</td><td>Each participant will be provided with a unique subject number to assist in the data entry into Microsoft Excel</td></tr>
<tr><td>Subject initial</td><td>Each participant will have their initials written on the survey to prevent duplication of response by the same participant</td></tr>
</table>

3.5.8 Outcomes Measured

3.5.8.1 Independent and Dependent Variables

Table 3.12: Independent and dependent variables for the cross-sectional survey

Specific Objectives	Independent Variables	Dependent Variables
To evaluate the influence of socioeconomic factors on quality of life among renal transplant patients	1. Educational attainment 2. Employment status 3. Household income	Post-transplantation Quality of Life of RTRS
To assess the financial burden of RTRS according to their socioeconomic status	1. Educational attainment 2. Employment status 3. Household income	Post-transplantation financial burden of RTRS

3.5.8.2 Covariates

Table 3.13: Variables studied in ReTRAPP based on literature review

No	Category	Variables
1	Socio-demographic data (non-medical data)	1. **Age** (Alkatheri et al., 2015; Chiu et al., 2004; Gentile et al., 2013; Mendonça et al., 2014) 2. **Gender** (Alkatheri et al., 2015; Gentile et al., 2013) 3. **Ethnicity** (Chisholm‐Burns et al., 2012) 4. **Marital status** (Alkatheri et al., 2015; Bunzel & Laederach-Hofmann, 2000; Khattak et al., 2010; Naiman et al., 2007) 5. **Geographical location** (Axelrod et al., 2014; Mathur et al., 2010) 6. **Educational attainment**(Alkatheri et al., 2015; Chisholm‐Burns et al., 2012; Gentile et al., 2013; Junchotikul et al., 2015) 7. **Household income** (Junchotikul et al., 2015) 8. **Employment status** (Gentile et al., 2013) 9. **Transplant centre** (Axelrod et al., 2010)

"Continued"

Table 3.13: Variables studied in ReTRAPP based on literature review

No	Category	Variables
2	Data post-transplantation (medical data)	• **Donor type** (Chisholm‐Burns et al., 2012; Gordon et al., 2010; Legendre et al., 2014) • **Comorbid conditions** a. **Diabetes mellitus** (Farrugia et al., 2014; Gordon et al., 2010; Nilakantan et al., 2016) b. **Hypertension** (Axelrod et al., 2010) c. **Cardiovascular disease** (Gordon et al., 2010; Jain et al., 2009) d. **History of malignancy** (Sahar Bayat et al., 2009) 3. **Perceived preparedness for transplant** a. **Physical** (Sieverdes et al., 2015) b. **Psychological** (Nejatisafa & Banihashemi, 2017) c. **Financial** (Cuesta-Briand et al., 2015) d. **Spiritual** (Sieverdes et al., 2015)] 4. **Perceived compliance to follow up appointment** 5. **Perceived compliance with medication** (Gaynor et al., 2014) 6. **Duration post-renal transplantation** (Schipper et al., 2014) 7. **Duration of dialysis** (Gordon et al., 2010; Meier-Kriesche et al., 2000)
3	Data post-transplantation (financial data)	1. **Personal or household income** (ACTION Study Group, 2015) 2. **Household composition** (Onwujekwe et al., 2010) 3. **Source of financing for medical expenses** (World Health Organization, 2007) 4. **Household expenditure** (Xu & World Health Organization, 2005) 5. **Cost of hospital admission in the last 4 weeks** - acute illness (Wagstaff et al., 2007) 6. **Number of comorbidities** – chronic illness (Wagstaff et al., 2007) 7. **Transport and food expenditure for routine follow up appointment**s (Xu et al., 2003)

3.5.9 Instruments Used

3.5.9.1 WHOQOL-BREF

A disease-specific Quality of Life (QOL) measure had not been developed for Malaysian patients' post-renal transplantation. Therefore, a generic Malaysian QOL survey was adopted by ReTRAPP to measure QOL of RTRs in Malaysia. The Malay version of the WHOQOL-BREF was derived from WHOQOL-100 after 10 years of research and development on QOL and health care (Skevington, Lotfy, et al., 2004).

The WHOQOL-100 was developed to emphasize the multidimensional concept for QOL (Noerholm et al., 2004). This instrument was the result of a collaborative effort of 15 field centres globally. A standardized international protocol was used to collect all the data required to develop this instrument. After testing in the 15 field centres, 100 items out of 236 items were selected, which formed WHOQOL-100 (Orley, 1996). The WHOQOL became one of the well-known instruments that were developed for cross-cultural comparisons of QOL and is now available in more than 40 languages internationally (Skevington, Lotfy, et al., 2004). The WHOQOL was considered an effective cross-cultural instrument to measure QOL with good to excellent psychometric properties of reliability and validity (Kalfoss et al., 2008; Skevington, Sartorius, et al., 2004)

The WHOQOL-BREF is a 26-item self-reporting instrument which measures health-related QOL with demonstrated validity and reliability (World Health Organization, 1998a). The WHOQOL-BREF is categorized into four domains of QOL and two items that measure overall QOL and general health, as shown in table 3.9. Based on WHO guidelines, the domains were not scored when more than 20% of items are missing or when two or more items are missed in the domain (or 1-item in the 3-item

social domain). The domains are composed of unequal numbers of items. Therefore, comparisons were made by transforming the score from each domain into a scale from 0 to 100.

Table 3.14: General and domain-specific items in the WHOQOL-BREF

General QOL			
1. The overall quality of health rating 2. Satisfaction with health			
Physical health (raw score range: 7-35)	**Psychological health (raw score range: 6-30)**	**Social relationships (raw score range: 3-15)**	**Environment (raw score range: 8-40)**
1. Mobility 2. Daily activities 3. Functional capacity 4. Energy 5. Pain 6. Sleep	1. Self-image 2. Negative thoughts 3. Positive attitudes 4. Self-esteem 5. Mentality 6. Learning ability 7. Memory concentration 8. Mental status	1. Personal relationships 2. Social support 3. Sex life	1. Financial resources 2. Safety 3. Health and social services 4. Living physical environment 5. Opportunities to acquire new skills and knowledge 6. Recreation 7. Transportation

Source: (World Health Organization, 1998a)

From the literature review, SF-36 is the most frequently utilized instrument to assess the QOL of the renal transplant recipient (Z. Butt et al., 2008). However, the 36-Item Short-Form Health Survey (SF-36) instrument only evaluates two domains which are physical health and mental health while the WHOQOL-BREF gives a broader measurement of four domains. Keown emphasized that QOL is a multidimensional measure comprising of physical, mental, social and economic components (Keown, 2001). Furthermore, the Malay and Chinese versions of WHOQOL-BREF has undergone validation to suggest equivalence to the standard English survey to measure QOL

(Hasanah et al., 2003; Liu et al., 2013; World Health Organization, 2004). Therefore, the survey is well suited to measure the QOL in Malaysia, even though its generic nature might result in some loss of sensitivity in detecting QOL across renal transplant specific domains. Permission to use WHOQOL-BREF was obtained from WHO prior to commencing data collection. (Appendix D)

3.5.9.2 Development of Financial Burden Survey

The survey was developed by drawing on a WHO initiative that looks into the household catastrophic health expenditure (Xu et al., 2003) as well as from previous surveys that were developed for local measurements for catastrophic health expenditure on cancer in Malaysia (Azzani et al., 2017). The domains were initially identified for the financial burden survey based on (Xu & World Health Organization, 2005):

1. Individual-level:
    - socio-demographic information (such as age, sex, education, employment status, residence)
    - individual income
    - health service financing
    - transportation expenditure for routine follow-up or treatment
    - medical expenditure for the last follow-up appointment
    - cost and diagnosis of hospital admission in the last 30 days
2. Household-level:
    - total household consumption (goods and services) and expenditure
    - combined household income
    - OOP health expenditure and private health insurance premium

This questionnaire was subjected to a content validation process before undergoing a pilot study for face validation at Tengku Ampuan Afzan Hospital, Kuantan.

3.5.9.3 Validation and Pretesting of Study Instrument

The finalized survey comprised of 3 segments; socio-demographics, QOL and financial burden. The financial burden portion of the survey had undergone content and face validation, while the QOL portion only underwent face validation because the WHOQOL-BREF had been validated in Malaysia (Hasanah et al., 2003).

3.5.9.4 Content Validation of Financial Burden Survey

The financial burden portion of this instrument was validated using experts in the field of renal transplantation, research methodology, health economics and public health. Table 3.15 provides the list of anonymised local experts that will rate each item on the financial burden survey that was developed.

Table 3.15: List of experts for validation of survey

Expert Code	Gender	Field of Expertise
1	Male	Non-Communicable Disease and Epidemiology
2	Male	Epidemiology and Biostatistics
3	Female	Epidemiology, Research Methodology
4	Female	Epidemiology
5	Female	Nephrology and Health Economics Research
6	Female	Nephrology
7	Male	Nephrology

The financial burden questionnaire was supplemented with a form for the experts to assess each item on the questionnaire. By using content validity index (CVI), the experts from different specialities were requested to study and rate each item on the survey on their necessity, relevancy, comprehension and clarity (Downing, 2003). A 4-point Likert scale (1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, 4 = highly relevant) was used to avoid having a neutral and ambivalent midpoint to rank each item (D. F. Polit et al., 2007; Zamanzadeh et al., 2015). Each item on the ReTRAPP survey was assessed by seven experts as mentioned earlier who provided a rating with points of 3 or 4 to be relevant based on their informed judgement (Zamanzadeh et al., 2015).

The CVI value computed for each item on a scale is calculated. It derived from the number of experts giving a rating of either three or four and divided by the number of total experts. Therefore, the CVI value provides the proportion of experts who agreed that the item applies to the research at hand. This method has been recommended by (D. F. Polit et al., 2007) as an appropriate indicator, based on a comparative evaluation of the CVI method.

According to Cohen, the person who developed the Kappa (κ), disapprove the use of simple proportion (e.g. CVI) is insufficient to validate an instrument (Cohen, 1960). Kappa (κ) index is a popular measurement that addresses the problem of CVI (i.e. a high proportion of agreement that may be due to random chance) by assessing both the bias and the precision between raters' ratings (Wan et al., 2015). Kappa value was calculated using the following formula

$$\kappa = \frac{(CVI - Pc)}{(1 - Pc)}$$

$$Pc = \left[\frac{N!}{A!\,(N-A)!}\right] \times 5N$$

K = Kappa value
Pc = probability of chance occurrence
N = number of experts
A = number agreeing on good relevance
! = mathematical symbol for the product of all positive interfere less than or equal to N (e.g. 5! = 5x4x3x2x1)

The standard criteria for acceptability require that the survey obtains a CVI value for each item ranging from 0.71 to 1.00, and the Kappa (κ) value ranging from 0.65 to 1.00 in the first phase of content validation. While for the second phase of content validation, a CVI value of 0.8 to 1.00, and the Kappa (κ) value from 0.76 to 1.00 is required (Natalio et al., 2014). However, Polit et al. recommended the CVI value to be higher than 0.78 and a Kappa (κ) value above 0.75 to be considered excellent regardless of the number of experts (D. F. Polit et al., 2007). Furthermore, Polit et al. rated that the values of CVI that were below 0.78 as good and 0.50 as fair, which would require revision and removal, respectively (D. Polit et al., 2007). Accordingly, ReTRAPP used the following values of 0.78 and 0.5 that are more conservative as standard for the validation process. Refer Appendix H for tabulated CVI and Kappa (κ) values each item in the financial burden questionnaire.

After conducting the initial phase of content validation, 25 items in the developed survey were considered acceptable with CVI between 0.78 and 1.00 as well as a Kappa (κ) value between 0.75 and 1.00. These 25 items were not required to undergo a second phase of content validity assessment because they have excellent CVI and Kappa values in the first validation phase.

Subsequently, in the second phase of content validation, all items that have a CVI and Kappa (κ) value below 0.78 and 0.75 respectively were revised according to the feedback received from the experts. These items that were rated as good were modified or reworded based on comments given by the expert to make the questions clearer and more comfortable for the participant to understand it. Examples of the four items that were revised after the first phase of content validation are shown in Table 3.16

Table 3.16: Items modified based on comments from experts for improving understanding participants

Item	Original Question	Revised Question
1	Current occupational status Self-employed ☐ Government servant ☐ Pensioner ☐ Private sector ☐ Unemployed ☐ Student ☐	Current occupational status ***Full time (permanent)*** ☐ ***Part time / temporary*** ☐ ***Full time (contract)*** ☐ Self-employed ☐ ***Housewife/ homemaker*** ☐ Student ☐ Pensioner/ Retiree ☐ Unemployed ☐
2	Employment status Permanent ☐ Pensioner ☐ Temporary ☐ Unemployed ☐	Sector of Employment ***Government*** ☐ ***Private sector*** ☐ ***Self-employed*** ☐ ***Not applicable*** ☐
19	**How do you** travel **to the** hospital**?** Car ☐ Bike ☐ Taxi ☐ Cycle ☐ Bus ☐ Walk ☐ Train ☐	**How do you** travel **to the** hospital**?** Car ☐ Motorcycle ☐ Taxi ☐ Cycle ☐ ***Uber/ Grab*** ☐ Walk ☐ ***Train (public transport)*** ☐ ***Bus (public transport)*** ☐
29	What is the degree of **difficulty paying** for your healthcare? Not at all ☐ A little ☐ A moderate amount ☐ Very much ☐ An extreme amount ☐	What is the degree of **difficulty paying** for your healthcare? Not at all ***1*** A little ***2*** A moderate amount ***3*** Very much ***4*** An extreme amount ***5***

Italic and bold denotes the changes made to the item on the survey

Item 6, which inquired about the number of individuals living with the RTRs was reworded and changed based on the feedback from the experts because it had a low CVI and Kappa for clarity (CVI = 0.571 and Kappa = 0.410). The initial three reviewers that provided a rating score of 1 or 2 were requested to re-evaluate Item 6 after it was modified based on the comments given. Table 3.17 shows the second phase of content validation for Item 6 and the finalised question that was validated after modification.

Table 3.17: Modification of item based on experts' feedback

Item	Original Question	Modified Question
6	Number of family members Adults …… Children …… Senior citizens living alone ……	Number of family members ***living together (including yourself)*** Adults (***18 years and above***) …… Children (***below 18 years***) ……

Italic and bold denotes the changes made to the item on the survey

3.5.9.5 Translation of Survey

The 29 items that constituted the final version was sufficiently acceptable to assess the financial burden of the RTRs after undergoing content validity. Subsequently, the translation of the developed survey was conducted. Two translators (a and b) who are proficient in English, as well as the mother tongue of the Malay and Chinese, were requested to forward translate the survey as mentioned earlier respectively (Montazeri et al., 2003). Step-by-step instructions were provided to the translator to translate the

survey, and it was emphasized to them that the cultural adaptation of the word of the phrase must be maintained and not the literal translation of the survey.

Subsequently, a similar approach was adopted by performing a back-translation of the Malay or Chinese version back to English by two independent translators (c and d) who are also proficient in English as well as Malay or Chinese. As mentioned earlier, the emphasis in the back-translation should be on cultural and conceptual adaptation and not a word-for-word translation of the survey (World Health Organization, 2009). Any discrepancies in the translation were discussed between the Researchers. The process was repeated until a satisfactory version was obtained. Due to the straightforwardness and generic nature of the questions, the translation and back translation was only conducted once. The whole process of translation for the survey is illustrated in Figure 3.9.

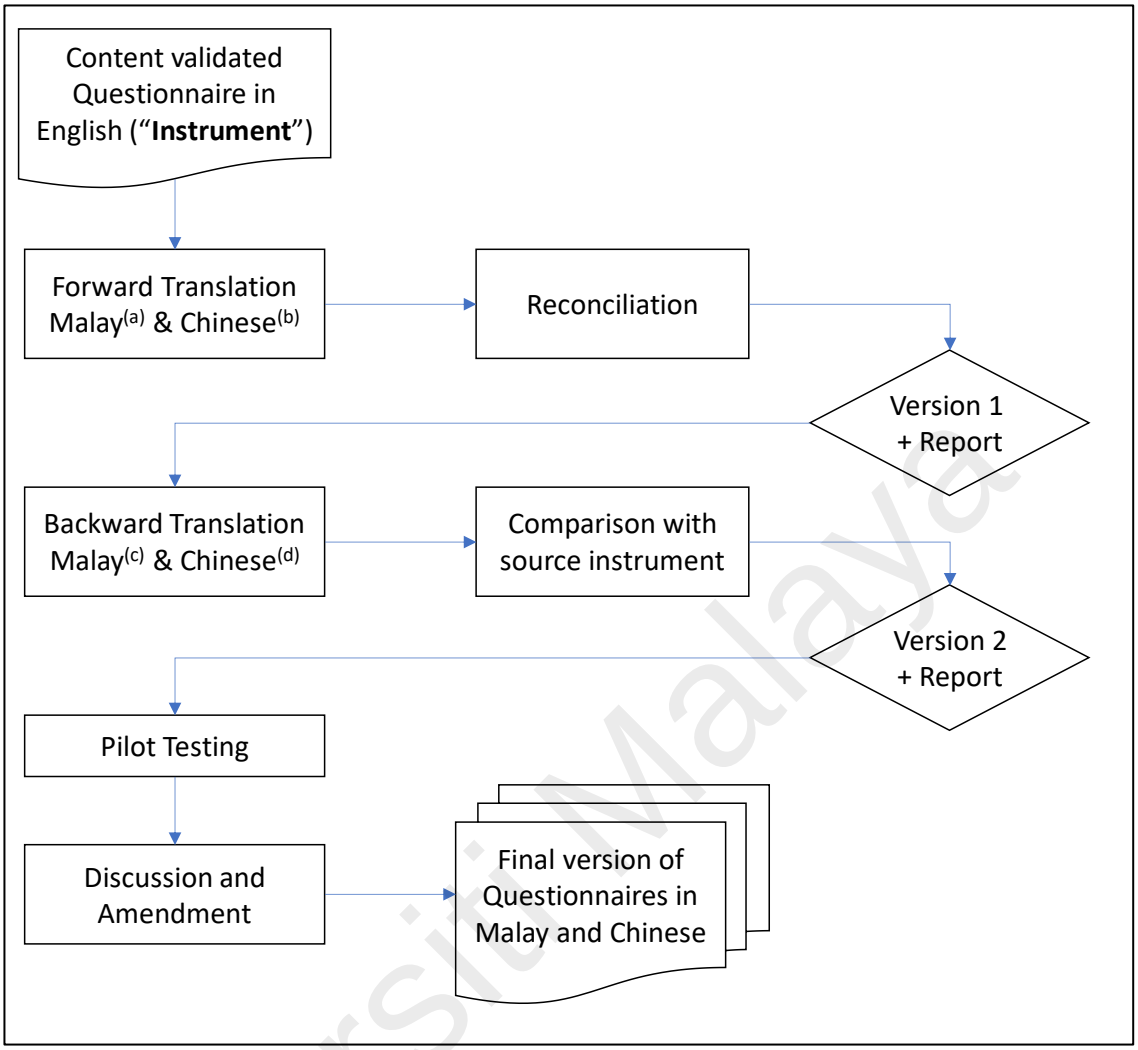


Figure 3.9: Steps in translation for ReTRAPP survey
a, b, c, d = translator

3.5.10 Pilot Study

3.5.10.1 Aim and Conduct of Pilot Study

The final version of the complete survey was tested in a pilot study which was conducted at Tengku Ampuan Afzan Hospital, Kuantan. This pilot study was performed after obtaining ethical approvals from various institutions concerned and permission from the head of the department of nephrology. The study site was selected because Kuantan has a city status like other major cities in Malaysia and has a tertiary hospital that provides

nephrology services to RTRs and manages 35 RTRs that would be sufficient for validation. The pilot study aimed to determine the appropriateness of the survey; WHOQOL-BREF to assess RTRs' rating of their QOL, while the financial burden component of the survey was to estimate RTRs' catastrophic health expenditure. Based on the literature, the suggested sample size for a pre-test survey ranges from 10 – 30 participants (Hertzog, 2008; R. Hill, 1998; Julious, 2005; Van Belle, 2011). The face validity of the survey was assessed with 20 participants recruited from hospitals in the pilot study. This aim of the pilot study was to determine the degree to which the instrument appears to assess the variable that it is supposed to assess by inquiring the understanding of the participants (Gravetter & Forzano, 2015). It also allowed the Researcher to know if there was confusion about any items in the survey and whether participants have suggestions for possible improvements to the items.

3.5.10.2 Face Validation of Complete Survey

First, a quick test was conducted to establish whether the participants met the eligibility criteria (listed in section 3.5.4.1). The Researcher approached the participants at the nephrology clinic during their routine medical follow up appointment with the nephrologist. If the participant met the eligibility criteria, the Researcher will explain the purpose of the study and obtain the informed consent from the participant before administering the survey. The Researcher handed the participant the survey form to be filled individually, while the Researcher waited for the participant to complete it. A total of 20 RTRs were recruited for the pilot study. The survey was made available to the participants in three different language versions for their convenience. Once the survey was completed, participants were thanked for their participation in the survey. Table 3.18 shows a summary of the participants' demographic who participated in the pilot study.

Table 3.18: Demographic information of participants in the pilot study

Characteristics	Total (N)	Number of participants, n(%)
Gender	20	
Male		11 (55)
Female		9 (45)
Age Group	20	
18 – 30		3 (15)
31 – 40		6 (30)
41 – 50		4 (20)
51 – 60		3 (15)
61 – 70		4 (20)
Ethnicity	20	
Malay		11 (55)
Chinese		7 (35)
Indian		2 (10)
Marital Status	20	
Single		4 (20)
Married		16 (80)
Level of Education Attaintment	20	
Primary Education		3 (15)
Secondary Education		12 (60)
Tertiary Education		5 (25)
Employment Status	20	
Employed		12 (60)
Outside workforce		1 (5)
Unemployed		7 (35)
Household Income	20	
< RM 1000		1 (5)
RM 1000 – RM 3000		12 (60)
RM 3001 – RM 5000		5 (25)
RM 5001 – RM 8000		2 (10)
Transplant Centre	20	
Local		11 (55)
Overseas		9 (45)
Donor Type	20	
Living		9 (9)
Deceased		11 (55)
Number of Co-Morbid Diseases	20	
None		9 (45)
1		6 (30)
2		3 (15)
3		2 (10)
Language selection for survey	20	
English		8 (40)
Malay		12 (60)

During the administering of the survey, a free text option at the end was utilized by 35% of participants. The Researcher requested written comments from the participants on suggestions for improvement and on items or issues that participants felt were under or over-represented. 67% of the feedbacks were made concerning the process of using the survey, and 33% of feedbacks were related to the survey in the context of their condition. Positive comments included issues such as being able to complete the survey without assistance, given sufficient time to consider their answers, finding self-administered survey less embarrassing than a face-to-face consultation. Negative comments included survey was too time-consuming or that the response options available were too limited (refer table 3.19).

Table 3.19 Feedback from participants on the survey

Themes	Positive feedback	Negative feedback
Layout	1. I think it is well tabulated in a very simple and easy to read format 2. Straightforward 3. Size of the font was readable	1. Pages should be numbered, and headings should be repeated for the questions that go onto the next page 2. Too many pages of questions
Content	Easy to understand	1. Too many questions to answer 2. Questions on household spending are too many 3. Hard to recall for last month's spending
Timing and location	Easy to survey while waiting to see the doctor	1. Time-consuming to do the survey 2. Takes 20-30 (minutes) to complete the survey

A few participants provided some suggestions after completing the survey. The participants felt that several items on the survey that they perceived could be improved.

The feedbacks were used to improve the understanding and quality of the questions that will be conducted in Greater Kuala Lumpur. Comments by participants and the observations during the administration of the survey were taken into consideration to revise several items on the survey (table 3.20).

Table 3.20: Revision of question-based on observation and participants' feedback

Original Question	Revised Question
Do you regularly miss your follow-up appointment? *Yes* ☐ *No* ☐	Do you go for your follow-up appointment regularly? *Yes* ☐ *No* ☐
Feedback from the survey: Question was structured in the negative, and participants prefer it in the positive form.	
Do you regularly forget to take your medication? Yes ☐ No ☐	Do you regularly take your medication as prescribed? Yes ☐ No ☐
Feedback from the survey: Question was structured in the negative, and participants prefer it in the positive form.	
Total monthly personal income (includes wages, salary, bonus, self-employment income, pension, retirement fund, interest, investment and rent) RM…….. If the amount is unknown, please choose the closest answer less than RM 1000 ☐ RM1000 – RM3000 ☐ RM 3001 – RM 5000 ☐ RM 5001 – RM 8000 ☐ RM 8001 – RM 10000 ☐ more than RM 10000 ☐	Total monthly personal income (includes wages, salary, bonus, self-employment income, pension, retirement fund, interest, investment and rent) RM……..
Observation from administrating survey: Participants were able to provide a rough estimate of their income. Therefore, the options for income were withdrawn to facilitate a better estimate for the financial burden.	

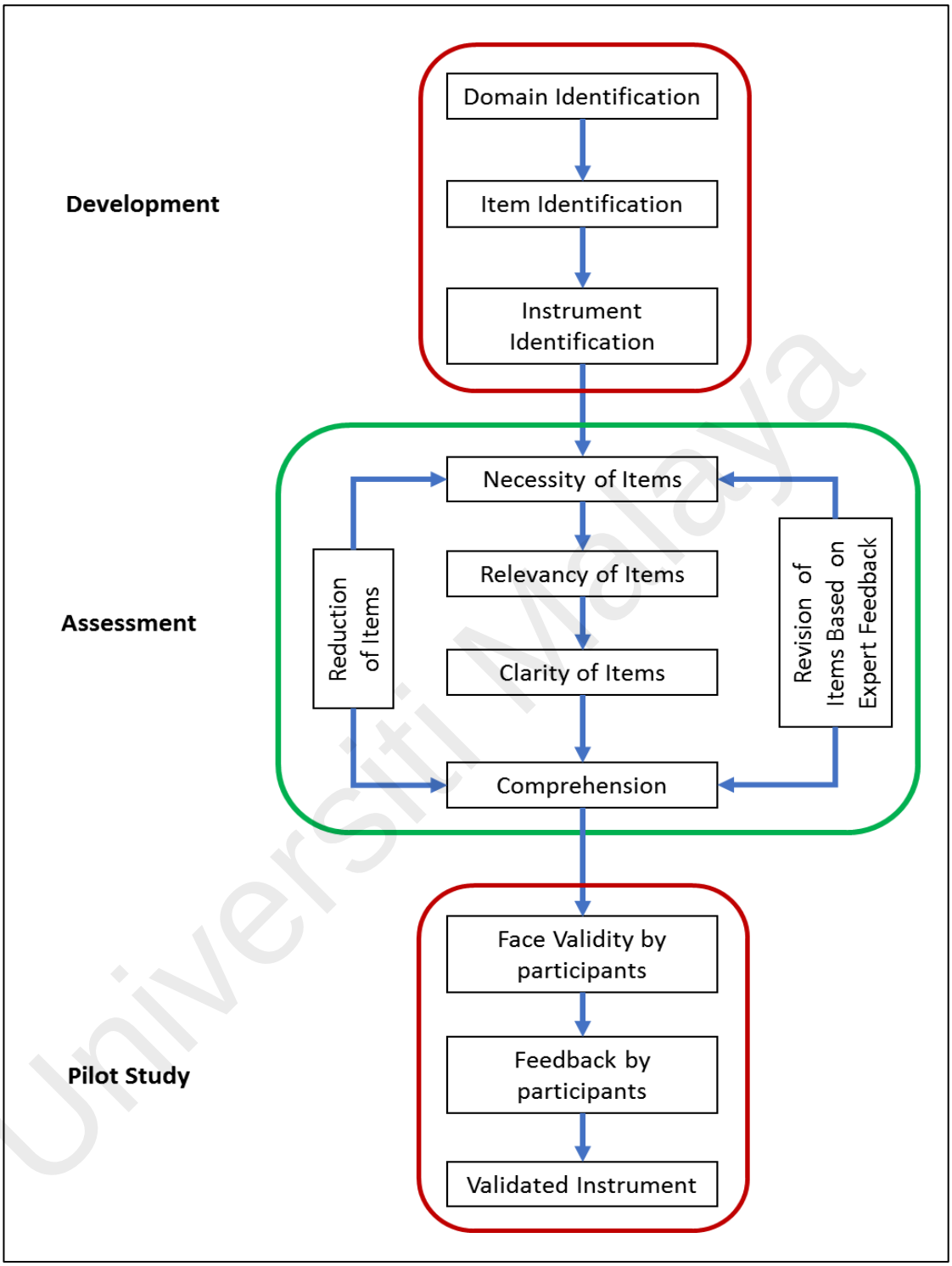


Figure 3.10: Summary of the validation and pretesting process of the instrument
Source: (Zamanzadeh et al., 2015)

3.5.11 Data Analysis

3.5.11.1 Data Entry

Initial data entry from the survey was performed using the Microsoft Excel Programme with password protection to ensure the confidentiality of the participants., the accuracy of the data coding and entry into the statistical computer program was determined to ensure the integrity of the data. It was done by doing a simple random sampling [using Excel sheet with command =RANDBETWEEN (1,350)] of 10% of the original questionnaire (n=40) from the total number that was administered (sampling frame=409). The survey forms were compared to the data transcribed onto the specially designed coded data sheets on SPSS. There were no discrepancies identified.

Data cleaning was also conducted by checking the data range for each variable entered to ensure that all data were entered within the designated ranges. Of the over 42,000 cells range examined, roughly about 3.2% of the cases (n=9) had at least one datum outside the delineated variable ranges. The original files for these cases were pulled and examined for accuracy. In each case, the data had been entered incorrectly (e.g. entering an additional decimal or a value that is beyond the range). These data were subsequently corrected for each of the cases, and the dataset was noted to be within the determined parameters before proceeding with data analysis

3.5.11.2 Transformation of scale score of WHOQOL-BREF

The mean score of each item in the domain of WHOQOL-BREF was used to calculate the raw score of each of the four domains. The possible raw score range of the physical domain is 7 – 35, the psychological domain is 6 – 30, the social domain is 3 –

15 and the environmental domain 8 – 40. Subsequently, the raw scores are transformed to scale of 0 – 100 using the following formula

$$\text{Transformed scale} = \left[\frac{\text{(Actual raw score – lowest possible raw score)}}{\text{Possible raw score range}} \text{ X100} \right]$$

Actual raw score	=	total value
Lowest possible raw score	=	4
Possible raw score range	=	difference between min and max raw score

The four domains were scored, labelled and transformed to a scale of 0 – 100 and can be used for interpretation and comparison to WHOQOL-100 (World Health Organization, 1998b).

3.5.11.3 Statistical Methods

For the multi-centre cross-sectional study component, analysis of ReTRAPP data was performed using International Business Machines (IBM) Statistical Package for the Social Sciences (SPSS), version 22. Baseline characteristics of the renal transplant recipients were tabulated. Descriptive analysis of survey data (quality of life – QOL) was performed to explore the characteristics and distribution of each variable based on the socioeconomic status (SES). The various domains (physical, emotional, social and environmental functioning) are being examined separately with the weighted mean of each WHOQOL domain and their standard deviation. These analyses helped explore the association of renal transplant recipients (RTRs) with SES that provided preliminary insight of factors affecting QOL. Associations between each WHOQOL domain and the SES variable were assessed using Kruskal-Wallis because the test of normality of the data distribution was not assumed. To make formal inference between SES factor and the

response variable – WHOQOL domains, general linear regression was utilized to ascertain its association. Linear regression models were adjusted for confounding (Rothman et al., 2008) by controlling age (years), gender, ethnicity (Malay, Chinese, Indian, and Others), and geographical location (City/Outside City). A trend test was used to assess a dose-response association of the SES and the different domains of WHOQOL. This trend test was performed by entering the SES variable in its ordinal scale as a continuous covariate in the analysis and checking for statistical significance.

Descriptive analysis of survey data (financial burden) was performed according to the SES. It is to explore the characteristics and distribution of each variable based on RTRs with catastrophic health expenditure (CHE) and those without CHE using Pearson's Chi-Square test for categorical variable and independent-sample T-Test for continuous variable. The World Bank's recommendation of CHE of 10% of household income was adopted (O'donnell et al., 2008). The Out-of-Pocket payment only considers both totals (direct and indirect) medical expenditure (refer Appendix I) and direct medical expenditure of RTRs for analysis and comparison. In the analyses, we divided households into Bottom 40%, Middle 40% and Top 20% classification according to the household income (Department of Statistics Malaysia, 2017).

The significant statistical socioeconomic difference for CHE is first tested by logistic regression. Adjusted logistic regression analysis was conducted to control for age (years), gender, ethnicity (Malay, Chinese, Indian, and Others), and geographical location (City/Outside City) to check if socioeconomic differential causes CHE (Rothman et al., 2008). A trend test was used to assess a dose-response association of the SES and the different domains of WHOQOL. This trend test was performed by entering the SES variable in its ordinal scale as a continuous covariate in the analysis and checking for statistical significance.

3.6 General Ethical Considerations

3.6.1 Procedure for Protection of Participants in ReTRAPP

The study proposal and any other documents including the Subject Information Sheet with Informed Consent Form and questionnaire, obtained ethical approval from the following Independent Ethics Committees (IECs)

1. Malaysia Research Ethics Committee (MREC) (Appendix A)
2. UMMC Medical Research Ethics Committee (Appendix B)
3. UKM Research Ethics Committee (Appendix C)

Unconditional approval was received from the IECs before the commencement of this study. Approval from the committee was documented in a letter to the Researcher specifying the study title, protocol number, the documents reviewed, the date on which the committee met and granted the approval, the name, occupation and institutional affiliation of the chairman and members of the IECs and provisions for periodic review if any. Any amendments to the protocol, other than administrative ones, must also receive approved from the IECs.

ReTRAPP was conducted following the ICH and Malaysian Good Clinical Practice (including the archiving of essential documents), as well as the Declaration of Helsinki (World Medical Association, 2013). The anonymity of all participants was maintained. Participants were specified on study documents by their participant number or initials and not by name or any identifiable details. Documents that identify the participants, e.g. the signed informed consent forms, must be maintained in confidence by the Researcher.

3.6.2 Participants Confidentiality

Participants' personal information obtained by the study was treated as confidential and are accessible only to the Researcher. Information was not disclosed to third parties other than for reasons below:

1. participant's request
2. independent ethics committee request/audit

3.6.3 Retention of Records

The Researcher arranged for the retention of study documentation until the end of the study. Besides, the Researcher has complied with specific local regulations/ recommendations with regards to participant study documents retention. It is recommended that the Research retains the study documents at least three years after the completion or discontinuation of the study (US Department of Health, 2006). All documents and dataset about ReTRAPP shall be filed and stored in a secured cabinet with lock and key or in a secure password-protected computer for three years.

3.6.4 Publication

Publication, either oral or written of the results, interim or final data will not occur without prior discussion and approval from all Researchers involved in ReTRAPP. The Researcher must ensure that the anonymity of all participants is maintained. The participants, however, will have no direct access to the study data.

Authorship will be determined by mutual agreement before the start of the study and will include lead authors for the initial presentation and publication of this study.

Criteria for selection of additional authors will be agreed before the start of ReTRAPP. All study data will be reported collectively without identifiable personal details when the findings of the study are published to protect the confidentiality of the participants.

3.6.5 Remuneration / Reimbursement

Remuneration in research includes payment or non-monetary reward to participants as compensation for time and inconvenience of participation. Remuneration can be either monetary (e.g. cash, gift cards and vouchers) or non-monetary (e.g. gifts and course credit) remuneration. There are two ways in which remuneration can be ambiguous because of

1. undue influence (offer of an excessive or inappropriate reward is made to obtain the consent of participation)
2. coercion (implicit threat of harm or negative consequences is intentionally presented by one person to another to obtain the consent of participation) (E. P. Williams & Walter, 2015).

Participants of ReTRAPP was not be compensated for the time and effort during their participation. Russell states that it is not necessary or required that participants who are involved in survey research receive monetary compensation for their participation (M. L. Russell et al., 2000). It supports the ethics of the research because the survey was administered during the routine follow-up appointments. The key-informants was offered honorarium as a token of appreciation, but none of the key-informants accepted it and encouraged the research and its dissemination.

3.6.6 Funding

No external funding for ReTRAPP was received.

3.6.7 Conflict of Interest

The Researchers involved in this study declared that there was no conflict of interest through their involvement in this study.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter details the findings of the ReTRAPP study derived from the qualitative study and quantitative study. The presentation of the findings would correspond to the sequence of ReTRAPP's research questions. The chapter will be divided into three components;

1. The qualitative study using the one-to-one in-depth interviews with key-informants for Objective 1 (Section 4.2)
2. The quantitative analyses of the retrospective longitudinal cohort study from the National Renal Registry for Objective 2 and 3 (Section 4.3)
3. The quantitative analyses of the multi-centre cross-sectional survey conducted by the Researcher for Objective 4 and 5 (Section 4.4)

4.2 Perceived Barriers and Solutions to Access Renal Transplantation in Malaysia

4.2.1 Summary

The qualitative component of ReTRAPP aimed to gain an understanding of the perspectives of key-informants on access to renal transplantation in Malaysia. The qualitative method was designed to explore the barriers and solutions to the renal transplantation system in Malaysia. A stakeholder analysis was used as a criterion for selecting knowledgeable key-informants for the in-depth interview. Rigorous attempts were made to approach key-informants involved in the renal transplantation system. As a result, six categories were identified from the stakeholder analysis. More specifically,

out of the six categories, at least one from each category was ensured. A key opinion leader in each category was deemed eligible and agreed to participate in the one-to-one in-depth interviews. A total of eight key informant interviews were conducted and audio-recorded with each interview lasting about one hour.

The first section describes the key-informants' background characteristics to provide the reader with a better understanding. The subsequent section will be followed by findings from the thematic analysis of the interview transcripts, which were organized into five main categories of themes and their sub-themes. Selected quotes in the key informant's own words that were relevant to the themes were presented as illustrations.

The qualitative component was explorative in outlining the barriers and solutions to access renal transplantation in Malaysia. The factors affecting the barriers and solutions were centred on the socioecological models. It provided an understanding of the environment surrounding the renal transplantation. Many of the key-informants described the patients as the deciding party for organ donation, and without their cooperation to inform family members, the consent for organ donation would generally be refused.

The lack of understanding of organ donation and renal transplantation by the community is also a major contributing factor to the reduced transplantation rate in Malaysia. It is coupled with the strong cultural beliefs of the community regarding the procedure that limits their interest. The key-informants suggested that better promotional efforts should be made to increase awareness and change the perception of the public. A common barrier that was highlighted by all key-informants was the lack of resources for renal transplantation. Some key-informants suggested pulling and consolidating the resources available to avoid redundancy. The lack of political will to support renal transplantation is one of the main factors from a systemic perspective, according to the key-informants. Few of the key-informants were suggesting innovative methods to improve organ donation rates while waiting for legislative and policy reforms.

4.2.2 Background Characteristics of Key-informants

The background profiles of the eight key-informants are summarised in Table 4.1

Table 4.1: General characteristics of key-informants

Key informant Code	Gender	Age (years)	Credentials	Duration of Service (years)	Category (stakeholder analysis)
KI–1	Male	58	Medical Practitioner in Urology (urologist)	30	Malaysian Urological Association
KI–2	Female	50	Medical Practitioner in Nephrology (nephrologist)	27	Malaysian Society of Nephrology
KI–3	Male	64	Medical Practitioner in Nephrology and previous Head of Nephrology Service (researcher)	40	Renal Transplantation Researcher
KI–4	Female	36	Medical Practitioner in Transplantation (policy advisor)	13	National Resource Transplant Centre
KI–5	Male	60	Medical Practitioner in Nephrology and Head of Nephrology Service (nephrologist)	35	Malaysian Society of Nephrology
KI–6	Male	59	Medical Practitioner in Urology (urologist)	32	Malaysian Urological Association
KI–7	Female	42	Medical Practitioner in Transplantation (policy advisor)	18	Transplantation Unit, Ministry of Health
KI–8	Male	60	Medical Practitioner in Transplantation (policy advisor)	38	National Transplant Council

To ensure the richness of the qualitative analysis, Table 4.1 also reported the duration of service and the essential qualifications of the key-informants. The above brief background for each key informant demonstrated some variation in the sample representations in the qualitative component of ReTRAPP. Other demographic details were not requested to maintain the privacy and confidentiality of the key-informants.

4.2.3 Findings of Qualitative In-Depth Interviews

The socio-ecological model (SEM) provided a multi-level framework for the Researcher to examine the range of factors that can influence the renal transplantation access in Malaysia. Themes from the in-depth interviews based upon this framework allowed comparisons to be made between living renal transplantation and deceased renal transplantation perceived barriers and solutions to access renal transplantation.

Results of the qualitative analysis were presented thematically. Themes that emerged from the interviews corresponded to the various level of the SEM. The findings were divided into the key-informants' perceived and experienced the following with themes as outlined (refer table 4.2)

1. individual factors,
2. interpersonal factors,
3. community factors,
4. institutional factors and
5. system/policy factors

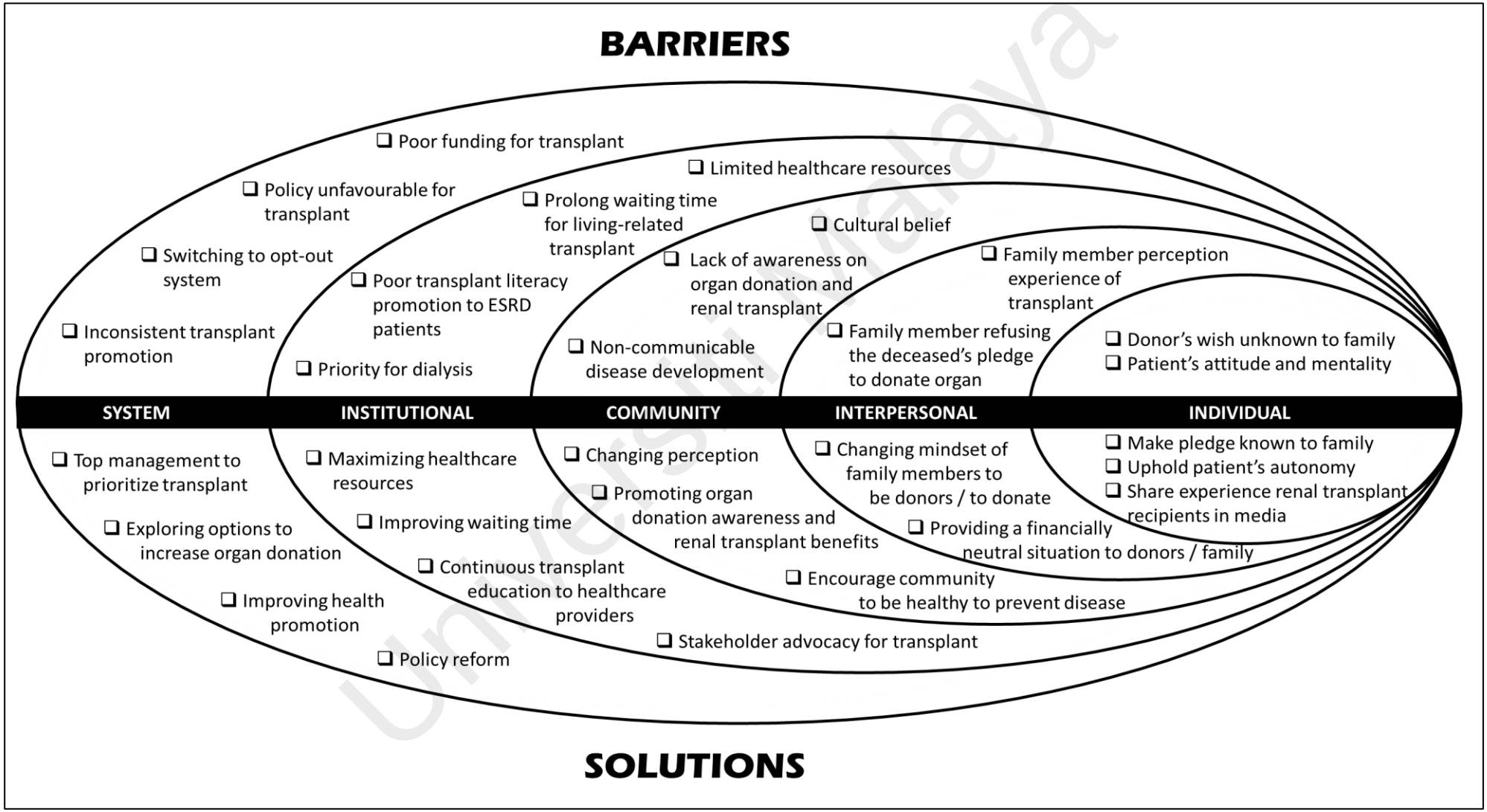


Figure 4.1: Socio-ecological model presenting barrier and solutions to renal transplantation

4.2.4 Barriers to Access Renal Transplantation

4.2.4.1 Individual-Level Factor

This section illustrates the key-informants' perception of ESRD patients in Malaysia. Four main themes emerged from the in-depth interviews with the key-informants in relations to individual factors; donor's wish unknown to family members, patient's physical condition for transplant, patient's perception and mentality and post-transplant outcome.

a. Donor's wish unknown to family members

As mentioned in earlier sections, the final decision for deceased organ donation determined by the family members of the deceased. Many a time, most organ pledgers did not make their intentions or wish to donate their organs known to their family members. Family members who did not know the deceased's preference were often not aware of each other's donation preferences and often rejected donation after brain death. It was mentioned by KI–6.

"Those who have actually pledged did not tell their family members their desire (to donate their organs). By instinct, their family members will not allow the organ to be donated. From my experience once, the family members may consider donating the organs of the deceased if the desire of the deceased is made know to them beforehand."

It was further corroborated by KI–8 who described that family members could consent for organ donation if they knew the preferences of the deceased on organ donation.

"On the other hand, can the family donate parts of me (the deceased), without asking me. Well, if they know your intentions, they can. How could they know my intention when we never talked about it?"

b. Patient's physical condition for transplant

Renal transplantation does not only depend on the availability of the organ but also the physical condition of the patient for surgery. As a surgeon, KI–1 described the predicament of ESRD patients on the waiting list for renal transplantation.

"We know that if you look at other countries, only 10 per cent of patients who are on dialysis are really (eligible) for transplant and the other 90 per cent are not transplantable because they are medically not fit. So usually they will take 10 per cent rule to say that 10 per cent of your dialysis patients are potentially fit for transplant. That is about it."

Besides this, patients who are suffering from other medical conditions would also hamper their chances for renal transplantation, as explained by KI–2.

"But sometimes during the transplant workout you will find a breast lump, you find a thyroid lump, you find some abnormality. So, these are the thing that keeps postponing the surgery or made them unfit for surgery."

c. Patient's attitude and mentality

The theme of patient's perception and mentality described the understanding of key-informants on ESRD patients through their doctor-patient communications when dealing with renal transplantation. Some patients would have a difficult time to accept the fact that they are suffering from ESRD, KI–1 revealed how ESRD patients are usually in denial of their condition.

> *"When he has renal failure, that is not a good time for you to discuss with him transplantation because you know that his thought process does not accept it. To get him to go and ask someone (family member) for a kidney to give it to him. When he says, what? I don't even need dialysis. At that moment he does not even accept the fact that he needs dialysis."*

KI–8 explained how patients would dictate the timing of their surgery and be fickle at the 11th hour on when the surgery should be performed.

> *"The surgeon calls one of the recipients, and he said that today he is not free la, can he come tomorrow. That is the patient's mindset. The patient has to come today, and I cannot keep the organ for you till tomorrow. So, these are the issues that we have to address for patients."*

On another note, KI–3 also described his experience that he had encountered previously on how patients would postpone the surgery because of the festive celebration.

"It's also about the mentality of the patients because they know the option of dialysis and take a tidak apa attitude[9] and postponed it because Raya[10] is coming, and they do not want to do it before that."

KI–2 shared a similar experience that frequently faced with ESRD patients who were scheduled for renal transplant surgery, causing a waste in hospital resources.

"Patients will suddenly postpone their operation or delay it because they want to celebrate Raya (festive celebration) or go on holiday. This results in the waste of OT time as well as the workup for the patients which would be invalid after a certain period."

KI–2 continued to emphasize the pertinent issue of the patient who would seek to undergo renal transplantation abroad without considering living-related renal transplantation.

"I asked why you don't want to do it here with one of your family members and so on. (She said) tak mahu susah[11], she does not want to trouble their family members and she has the money."

[9] *Tidak apa* attitude is a Malaysian expression to describe the inclination of the person to be unconcern about anything or to adopt a disinterested demeanor (Dickin et al., 2014)

[10] Raya is a festive celebration by the Muslim to celebrate the end of the fasting month of Ramadhan.

[11] Tak mahu susah is a Malay phrase that means the patients does not want to trouble

4.2.4.2 Interpersonal-Level Factor

In renal transplantation, family members play a vital role in both living-related and deceased renal transplantation. Each key informant would have been communicating with the family members at some point or another to discuss organ donation and renal transplantation. In this level, only one major theme was consistently described by the key-informants on family members regarding their perception of organ donation. Due to the dichotomy of renal transplantation, the themes would be divided based on the type of organ donation

a. Family members' perception of living-related renal transplantation

For the living-related renal transplant to materialize in Malaysia, the donor must be a first-degree family member or emotionally related to the recipient. Therefore, key-informants would have experienced and understood the perception of the family members during discussions. Overall, three themes emerging from the in-depth interviews that were related to living-related renal transplant; fear of organ donation, coercion into donating, inconvenience as a donor.

i. Fear of organ donation

KI–7 lamented that even with the active promotion of living-related renal transplantation done by the Ministry of Health with the knowledge that Malaysians are a family-centric society, the family members are not keen to donate because of fear.

"Even if we promote living kidney donation, still they are having issues of family members coming to donate. That's what's been told to us. So, we are closed knitted but somehow, we are not so willing, I guess. I am not sure why but maybe because they are afraid of their own wellbeing after donating the kidney."

Donor's fears were further explained and defined by KI–5 and how it affects the family members decision to donate their organ.

"The patient (recipient) may wish to have the transplant. But the pressure, (namely) the physical pressure, financial pressure, social pressure is on the donor. The donor does not get anything (out of the organ donation)."

ii. Coercion into donating

One of the key-informants described one of his experience with a donor who did not voluntarily consent for the organ donation. KI–9 set the story of how a donor was chosen in a family.

"What the family would do, the family will pre-select you, and normally the family would pre-select who, the one that is the least educated."

Subsequently, KI–9 described how the donor would seek for help from the healthcare provider to avoid donating his / her organ.

"When running this transplant programme, this donor is a neighbour who came outside my house and cried, (saying) I do not want to donate, I've been forced by the family, can you help cheat the blood result for me."

iii. Inconvenience as a donor

The transplant centres are all located in the Greater Kuala Lumpur, and the patients (recipients and donors) must travel from out of state to have their laboratory and imaging investigations performed. A lot of the hidden cost to the donor during pre-transplant is unknown to most as described by KI–5.

"But in the process of donating, there is cost involved. People will have to come to travel to hospital, to have blood checked, urine checked, x-rays, radioisotope, physical assessment by doctors, and revisit on numerous times. These hospital visits will not only incur cost to them but will also affect their employment."

Unfortunately, as donors, their medical insurance does not cover their pre-transplant laboratory and imaging assessment. It was informed by KI–3 on the financing difficulties for donors at the key-informant's private practice.

"So, what I do in private practice, I (will) do a staging workup. Once they passed a certain stage, you can't do the test, (because) it can be expensive, but only a few patients can do that cause the donors are not eligible for insurance, (however) the patients are eligible for insurance."

KI–5 elaborated further on the financing by describing the hidden cost for donors who resides far away from the Greater Kuala Lumpur and the difficulties they faced during the post-transplantation recovery and follow-up.

> *"For some of them, the travel is not just from Jalan Ipoh to HKL[12], it may be from east coast coming to HKL, it may be Sabah or Sarawak, coming to HKL. After transplantation, they had to stay here for weeks to months to make sure that they're stable before they go home. Where they stay, how much money they need for food, for accommodation are things that we may not be aware and concerned."*

KI–2 described a situation when a donor was forced to apply for unpaid leave when her medical certificate from the government hospital was refused by her company.

> *"... the company she worked for did not allow her to take the six weeks MC[13] that she was given by the government hospital after the surgery and she had to take unpaid leave."*

b. Family members' perception of deceased renal transplantation

As described in the literature review, the final decision to donate the organs of deceased patients falls solely on the family members. The key-informants would have previously experienced approaching the family members of the deceased to obtain

[12] HKL denotes Kuala Lumpur Hospital

[13] MC is an abbreviation for a medical certificate from a qualified practitioner confirming the status of the health of the patients. It is issued for specified periods consistent with the anticipated incapacity of an employee, which is certified by a practitioner, to be unfit to discharge the normal duties or deemed serious enough to warrant recuperation. (Director-General of Health Malaysia, 2009)

consent for organ donation. From the key-informant's perspectives, two major sub-themes are arising from this theme.

i. Family member refusing the deceased's pledge to donate organ

Majority of the key-informants cited this as the major hindrance in organ donation. As the final decision for organ donation lies with the family members, KI–7 attributed the family members' refusal to culture.

> *"In Malaysia, we are still very culturally, we are very close-knitted family members and without family members' consensus to decide (if) they want to donate the (deceased) organs. It is actually one of the major factors that are actually the major hindrance. Family refusal (to donate the deceased's organ)!"*

KI–5 illuminated on how the process of procurement is conducted in the hospital intensive care unit (IUC). Once suitable donors were identified, family members of brain-dead patients were approached for organ donation, but the majority would refuse consent.

> *"The tissue organ procurement team that goes around identifying the potential brain-dead individual in ICU and then looking at the possibility that they may actually be a potential organ donor. When brain dead ascertained, certified and family (was) approached, 50% of family members would refuse either to donate or refuse to allow the organ to be taken or refuse to make a decision (on organ donation)."*

Some of the family members would object to the deceased's pledge to donate or change their mind by overwriting the consent as experienced by KI–8.

"The donor's relative can come and stop at the eleventh hour and say no, we refuse to let you take although I [the deceased] have said you [the doctor] can take my parts, my wife or somebody can say no I won't let you take and then you can't proceed, you see."

ii. Perception reinforce refusal

KI–2 illustrated the experience of family members expressing their refusal due to fear of how the deceased's body will be treated during organ procurement.

"At the end of the day, it is the family who decides to donate or not to donate the organs. In my experience, most of the relatives assumed that the body would be mutilated if they consent for organ donation."

This notion of bodily harm to the deceased's body was fortified by the misconception of the family members (includes healthcare providers) on what is organ procurement about as experienced by KI–1.

"Even when the deceased who have pledged their kidney, the family still has the onus to say no. Usually, they will say that they don't want to inflict more injury to the patients. Thinking that the patients can feel the pain. And it's not only among the layman, even medical staff sometimes feel, you shouldn't go and cut people up."

4.2.4.3 Community-Level Factor

The role of community-level factor refers to the relationships and networks among individuals that may influence renal transplantation in Malaysia. Four themes emerged from this factor; community's perception of living-related transplantation and deceased renal transplantation, lack of awareness on organ donation and renal transplantation and non-communicable disease development.

a. Community's perception of living-related renal transplantation

There is a general perception of the public that by donating a kidney to your family member, it would have severe repercussions for their wellbeing as stated by KI–8.

"Half of the members of public, who are in the position to make the decision to donate their organ to their loved one, but they do not may be due to concern for their health and safety."

b. Community's perception of deceased renal transplantation

KI–7 explained that in Malaysia, the deep-rooted cultural belief that has prevented the community from accepting organ donation as part of their social responsibility.

"Here in Malaysia we still have a strong cultural belief actually against donation, even though, even though after we have promoted, even though we have taken into consideration the fatwas and everything we have worked for to show that the fatwa allows it, there is still resistance to donate (their) organs."

The public has a strong cultural belief regarding deceased RT that prevents them from donating because some believed that organ donation is similar to mutilating the dead. It violates the person's dignity (Ministry of Health Malaysia, 2011d). This cultural misconception is associated with religion as backed by KI–4.

"Most are scared to donate after death as they worry that it may bring repercussions spiritually…. Most of them feel that donating an organ is something that violates the human body."

c. Lack of awareness of organ donation and renal transplantation

KI–1 attributed that the lack of awareness among the public on organ donation was due to the delay in promoting organ donation to the community.

"We are actually behind time. So, of course, you cannot expect the rate of pledgers to be so high because we have started very late. We should have started a long time before."

On the other hand, KI–3 opined that it is the reduced functional literacy rate in Malaysia that hinders the public from capturing the information on organ donation and renal transplantation as compared to other developed nations.

"But in this country (Malaysia), many are illiterate. When I talk about literacy, it's (means) functionally literate, i.e. they can write and read. But how many can understand the implication of the consent and so on."

KI–4 mentioned that the education system in Malaysia needs to balance the promotion of disease prevention as well as on awareness and education on organ donation and transplantation.

> *"There must be a balance of disease prevention awareness and education as well as transplantation and donation education in schools. One can never prevent disease 100%; hence the answer to saving lives is organ donation and transplantation where possible. Unfortunately, the current education system does not provide such syllabus."*

It was substantiated by KI–2 provided insight into her child's educational structure that includes organ transplantation in the United Kingdom syllabus that is absent in Malaysia's syllabus leading to poor awareness among the public.

> *"Organ transplantation is not in the local education system, because two of my older daughters went to a local school, and they were no exposure to it. My youngest daughter did Cambridge (IGCSE Centre)[14] , and there is a section on organ transplantation in their curriculum."*

d. Non-communicable disease development

The rise in non-communicable diseases (NCD Risk Factor Collaboration) was heavily discussed by all the key-informants. NCD are the primary causes of ESRD in Malaysia that led to the increasing demand for renal transplantation. Two major sub-

[14] IGCSE is International General Certificate of Secondary Education for the end of secondary school before proceeding to pre-university (IGCSE Centre, 2018)

themes emerged from the interviews which pointed to the unhealthy lifestyle practices as well as the perception towards the treatment of NCD.

i. Unhealthy lifestyle practices

Majority of the key-informants provided similar insights about the community's lifestyle that are not conducive for health leading to ESRD. KI–6 attributed it to physical activities.

> *"It's due to the lifestyle because we know that there is an increasing incidence of diabetes. So, it can be related to that in terms of physical activities which has reduced significantly compared to previously."*

KI–2 was worried when discussing the accessibility of unhealthy food, emphasized that the dietary habits of the community, which caused the rise in obesity and ultimately leading to metabolic diseases.

> *"Unfortunately, when you visit the park during the weekend, you will notice the sale of unhealthy food is at every corner selling goreng-goreng[15] food, high sugar and calorie food. This is so unhealthy, and that is why you see everyone is overweight and why our country has the highest obesity rate in the region."*

[15] Goreng-goreng is a Malay word which means fried

ii. Distrust towards medical treatment leading to poorly controlled NCD

The poor compliance of medication in the community is related to their perception of the western medication as described by KI–1.

"Malaysian population is very stubborn when it comes to taking their medicine, and it has got a lot to do with their own cultural and religious believes. They believe that taking western medication is not good for them."

KI–1 further elaborated that this poor compliance is the culprit for the uncontrolled diabetes mellitus and hypertension.

"They think they are getting the complication because of the medicine and not because of the disease. So, because of this, the primary treatment of diabetes and hypertension is so poor, in this country."

4.2.4.4 Institutional-Level Factor

Institutional level factor refers to the healthcare providers at the front-line who handles renal transplantation. It described the barriers that were faced by healthcare providers. Five themes emerged from this factor; limited healthcare resources, prolonged waiting time for living-related renal transplant, lack of education and promotion to ESRD patients and priority towards dialysis.

a. Limited healthcare resources

Almost all if not most of the key-informants indicated that resource is the leading cause that limits the progress of renal transplantation in Malaysia. The four sub-themes for resources emerged; human resource, infrastructure, medicine, and supporting services.

i. Human resource constraint

The number of healthcare providers involved in renal transplantation is insufficient to cater to the needs of the Malaysian population, as explained by K1–7.

> *"Yes, we don't have many (experts) for transplant. Our numbers are very low unfortunately to cater for the whole of Malaysia."*

The current practice of one doctor performing multiple duties was described by KI–5 as burdensome to the transplant surgeon.

> *"The surgeon doing transplant is also the surgeon doing many other things as well. So, it is extremely exhausting for the individual."*

Personnel who are tasked to handle renal transplantation are not the experts in the field as described by KI–3.

"The nephrologist that was in charge of the transplant was sent to the UK to train in glomerulonephritis. (But) when she came back, no one was handling transplant, so she was put there."

KI–1 lamented that as a transplant surgeon, the requirement is to operate on both living-related and deceased renal transplantation, but no incentives were provided. Overseas practices were cited as a comparison.

"If you're a transplant surgeon, you cannot say, "no, no, no, I will only do the living, and I'm not going to do the deceased", you know, it comes hand in hand. So, you are given a certain payment overseas, although not much."

The exodus of transplant surgeons to the private practice was echoed by KI–6.

"They have moved on to private practice and they are not doing transplant anymore."

ii. Infrastructure inadequate

Infrastructure in this context refers to the facilities in the hospital that are utilized for renal transplantation. The main facilities in question that were discussed by the key-informants are mainly the intensive care unit (ICU) and the operation theatre (OT). The challenge to secure OT slots for transplant surgery was lamented by KI–6.

"The limited availability of operating time available for any procedure. It's not necessarily for transplant alone."

KI–5 further described the situation in the hospital where renal transplant surgery is sharing the infrastructure for other specialities as well.

"…… the OT used for transplant is also OT use for many other things as well. So, we are competing for resources with other departments as well."

Besides the OT, post-surgical care requires ICU monitoring and KI–2 illustrated what the current conditions of these facilities are.

"Another issue with the kidney transplant is the facilities in the hospital, we are conducting the transplants in OT and ICU that are not conducive for the transplant patient. The OT and ICU building are currently placed behind the A&E that is debilitated and not functioning properly."

KI–2 elaborated further on the ICU condition utilized in the post-transplant surgery care in the hospital that is inappropriate for post-transplant patients.

"The current ICU beds that we are using are too close to each other, and the ICU does not have isolation area for the transplant patients."

iii. Supporting services non-complementing

Supporting services encompasses the laboratory or imaging services that are required by the transplant team to work up the donors are inadequate as mentioned by KI–8.

"Here in Malaysia unfortunately, the people are prepared to donate, but our system (supporting services) does not facilitate that donation process."

KI–7 supported the notion that the transplant team has to compete with other teams to access the imaging services for the patients.

"The supporting department does not only cater for transplant, [but] they also cater for even other services, or other departments as well right, so, of course, there'll be issues, because the number of slots even for CT scan[16], for MRI[17], of course, that would be one of our challenges."

Laboratory services, as described by KI–3, is a challenge for the transplant team to investigate the patients for transplant in an acceptable timeframe.

"To do a CT scan, to look at normal renal artery for transplant, radiology usually will give two months appointment. To do HLA-typing[18] or haplotype[19] typing, IMR[20]

[16] CT scan is referred to as computerised tomography (CT) scan that uses a computer and X-rays to produce detailed images of the structures inside of the body

[17] Magnetic resonance imaging (MRI) is an imaging that uses strong magnetic fields and radio waves to create detailed images of the structure inside of the body

[18] HLA-typing is human leukocyte antigens typing used to match the recipient and donor to ensure that the renal graft is not rejected by the recipient (Takemoto et al., 2004)

[19] A haplotype typing used to match the recipient and donor by comparing their genotype (Pedron et al., 2003)

[20] IMR is the abbreviation for Institute for Medical Research serve as the national reference centre for transplantation

would do once a month, (and) sometimes they (would) said no reagent and need to wait for another month."

The lack of incentive to the transplant surgeon encouraged them to move to private practice, as stated by KI–3.

"Many of them nowadays want to jump to the private sector after a few years of experience in urology they want to jump. There is no money in transplant in the public sector, so they don't want to do it."

b. Prolonged waiting time for living-related renal transplant

The prolonged waiting time described by KI–1 was partly due to the delay in assessing the patients that were required for the living-related renal transplantation

"Because there are so many patients. This guy would say, we ask for the cardiac appointment, they said in six months time, for a CT scan, these guys said, appointment in six months time. So, there's a lot of dilly dally here you are now."

KI–2 pointed out that previously the whole assessment period for the patients would be prolonged partly due to the delay in cardiology assessment

"It may take up to 2 years because sometimes it will take them 8 months to a year to get a cardiac assessment in the hospital."

This delay in the assessment would, in turn, invalidate the results because the imaging has expired and required to be redone again as mentioned by KI–8 who was frustrated with the process

"Problem of workup of a patient after two to three months, if you don't do it, you have to work up the donor again, so by the time you want to put the patient on the table, it's too late. You know, if you are waiting for two years, you have to go back and re-work up the patient again."

c. Poor transplant literacy promotion to ESRD patients

The lack of awareness amongst patients could be attributed to the failure of healthcare providers to educate their patients, as described by KI–1.

"Maybe the doctors are also not doing enough to drum into them, you know, the importance (of renal transplant)."

It was supported by KI–2 when discussing the issues of public awareness of chronic kidney disease and renal replacement therapy, especially renal transplantation.

"The attending doctors should expose their patients about kidney failure when they are diagnosed with chronic kidney disease and educate them about kidney transplant and not just dialysis."

Besides the patients, healthcare providers did not educate the organ donation pledgers to engaged with their family members regarding their intention to donate their organs, as explained by KI–6.

"Those who have actually pledged should tell their family members their desire. Then their family members will not go against it. So, I think those who pledge need to be educated to tell their family members."

d. Priority for dialysis

The process of providing information on renal transplantation is time-consuming and with most healthcare providers overworked, and the nephrologist would choose the more comfortable option by suggesting dialysis as KI–3 mentioned.

"The real reason is because to counsel for transplant, (it) will take many hours. Repeated counselling. Unless you have a dedicated team, usually the nephrologist seeing the patients for the very first time, they will say dialysis, PD."

The decision of nephrologist to choose dialysis over transplant is partly due to their involvement in a dialysis centre, and a disappointed K1–8 described the current situation.

"The problem is because given that I'm the nephrologist sitting in particular hospital A, and I'm the affiliated nephrologist to a nephrologist centre in the same town, is there any strong indication for me to put this patient on a transplant programme or is it better for me to put this person on a dialysis programme in the centre on which I am the affiliated nephrologist, because, as an affiliated

nephrologist to a centre, I'm paid a certain amount per head per month per patient."

Not just healthcare providers, even funding agencies would give financial support for ESRD patients for dialysis as KI–5 lamented.

"Insurance, SOCSO[21] and so on decide on how much money patient gets, for what treatment, but then there is no policy in those funding agencies to say that we prefer transplant or if you had no contraindication you need to go for the transplant. But they always have a policy for dialysis."

4.2.4.5 System-Level Factor

System-level factor refers to national legislation and policies that affect renal transplantation in Malaysia. Although these policies may not have been created to disadvantage renal transplantation. However, the unintended consequence results in a clear disadvantage for renal transplantation. Themes emerged from this factor; inadequate funding for transplant, policy unfavourable for transplant, policy not updated, switching to an opt-out system and transplant and transplant promotion ineffective.

[21] SOCSO (Social Security Organisation) act as a compensation body for employee's safety.

a. Limited funding for renal transplantation

Transplant services funding was limited as described by KI–7 when compared to other modalities like dialysis.

"Yes, we need more funding for kidney transplant of course. Our budget now pales in comparison to dialysis."

KI–2 shared the budgeting of the nephrology service, which is mostly channelled to dialysis program.

"The funding of nephrology is mostly channelled to dialysis. Recently the government just introduce more subsidy to dialysis in the country which will allow the patient to pay only RM10 for each dialysis."

KI–8 was extremely agitated when describing the disproportional funding between transplant and dialysis.

"It is in an embarrassing state, and it is a humungous financial burden to the government of Malaysia to keep dialysis people."

b. Unfavourable policy for renal transplantation

KI–5 described how the policy does not support transplant because there is no political gain even when renal transplantation provides a better quality of life and is cheaper to finance.

"If there is any need to save public money it would be the poorer countries like us, but we choose to spend on a more expensive dialysis machine, incentivise dialysis with the promise of a lower quality of life and lower survival rate compared to a more effective transplant that is cheaper. It is more fashionable for people to come to the podium on national television or newspaper to show the dialysis machine."

The policy implemented by the Ministry of Health does not govern the hospitals of the Ministry of Education, which may be problematic mentioned by KI–6.

"The MOH policies must be inclusive of the university hospital. So far, the policy has not been inclusive."

KI–4 described that the current renal transplant policy has been unchanged since 2007 and requires a new revision to reflect the current best practice.

"Our current policy is rather backdated in 2007. It urgently needs updates and improvements in all parts of the policy."

This statement was reiterated by KI–2, who felt that old guidelines and policy needs to be updated to be more productive.

"The practice of the current policy has been there for many years. It has not shown to be effective. Why do we still practice it when you know it doesn't work. What they are doing is recycling the guidelines hoping for a different outcome."

KI–5 described a situation where there is inconsistency with the policy for living unrelated transplant whereby the Unrelated Transplant Approval Committee can only decide on donation from family members beyond second degree, and not unrelated individual as the name of the committee says

"If a stranger, a friend, a boyfriend, a girlfriend wants to come forward to pledge organ or to give the kidney to their friend, neighbour or childhood friend or stepfamily member who suffer from kidney failure, they will not be accepted because the detail of that guide only confines the assessment of the committee to those who are related beyond second degree."

c. Switching to the opt-out system

The "opt-in" system currently practised in Malaysia requires that the donors provide informed consent before a person's organ can be donated (Malaysian Medical Council, 2006b). The organ procurement team may proceed to harvest the organs upon the death of the donor or if circumstances allow for procurement. However, the immediate next-of-kin may refuse the organ removal ("Human Tissue Act," 1974). It would dampen the efforts of the healthcare system to encourage more deceased renal transplantation. Although the change system to "opt-out" would increase in the organ donation rate, the public is not prepared for it suggested by KI–1.

"In terms of legislation, we cannot go the Singapore way, where you have the opt-out rule. That's too far in the future. We're not ready for that. You cannot introduce an idea which is not ready yet, you know. People will take offence, you know. That you're forcing me to, you know."

KI–7 advocated the notion that the rejection of the opt-out system stems from the deep cultural belief of Malaysians.

"To decide whether we're going to do opting in and opting out, I think we have to take into consideration of the public's perception because here in Malaysia we still have a strong cultural belief actually against donation. If we were to do opting-out system now, we're going to create more resistance and more dissatisfaction from the public."

While KI–6 described Malaysia to be more populated and more demographically diverse than Singapore, which is much harder to manage.

"Singapore's society is slightly different in that sense, that they are more of a controlled society in many ways. And it is a smaller population and so it is easier to control. Where else Malaysia has a bigger population and more multicultural with more issues."

d. Inconsistent transplant promotion

The promotion of renal transplantation was conducted inconsistently as noticed by KI–6. The public awareness was only temporary when the first heart transplant as an example as KI–6 further explained.

"Promotion is not effective. It is not consistent. We do, and we stop. It's like what happened a few years ago when we did the first heart transplant. We had an increase in the number of people who donate for a brief period."

On the other hand, KI–1 described the promotional program for renal transplantation was only implemented recently.

"Of course, we started very very late, all these 'Jom Derma' popping up, it just started a couple of years ago, you know. We are actually behind time."

4.2.5 Solutions to Improve Access to Renal Transplantation

To provide insight for stakeholders seeking to address and improve the issues of transplantation service in Malaysia, ReTRAPP illustrated the solutions at every level of the socio-ecological model as described by the key-informants.

4.2.5.1 Individual-Level Factor

At the individual level factor, the themes that emerged were to make pledges known to family members, uphold patient's autonomy and share experience by renal transplant recipients.

a. Make pledges known to family members

The main issue, as mentioned earlier, was the lack of communication between pledgers and family member. KI–6 suggested that healthcare providers educate pledgers to communicate their intention to donate to family members.

"Those who have actually pledged should tell their family members their desire. Then their family members will not go against it. So, I think those who pledge need

to be educated to tell their family members. From my experience once, the family members know the desire of the deceased beforehand, they will not go against it."

b. Uphold the patient's autonomy

KI–8 went further to propose that the donor's consent should be final and must not be overruled by their family members.

"If I have made an informed consent to donate, can my family stop me. If you ask me, technically they should not because this is my wish, how can they overwrite my wish. I could have made it at the time when I am sane when I had all my faculty intact, and I was a major. So that part of it I think we have to relook at."

c. Share experience by renal transplant recipients

KI–4 stated that transplant recipients must share their renal transplant experiences and successes with the public.

"Kidney transplant recipients need to speak up and share their experience with the public."

KI–8 elaborated how healthy renal transplant recipients should be engaged for publicity in the media to show the public how well a transplant recipient can be.

"The transplant recipients who were transplanted 35 years ago could have written up done about them in the Malay papers, the Chinese papers, whatever paper la.

Put them on television to (tell the public) that Oh My God!!! these patients have been living for so many years with a (transplanted) kidney and he is fine."

4.2.5.2 Interpersonal-Level Factor

The interpersonal level factor provided two themes; change the mindset of family members and provide financially neutral acts to donors and family members based on the dichotomy of renal transplantation.

a. Living-related renal transplant

i. Ensuring donors are aware that their wellbeing is looked after

KI–6 described the process of investigating the donor to ensure the suitability for transplantation and that the donor's health will not be in jeopardy.

"(Donor will) go through a lot of test and doctors need to make sure that the donor is protected, and we have to be very careful to ensure donor knows their safety and is well taken care of."

ii. Providing financially neutral acts to donors

The notion of providing free hospital care to living-related donors by the government was reiterated by KI–5 as goodwill for organ donation.

"The government must give incentive for live donor especially kidney donor, to waive them from any charges, so they don't have to pay for transplant workup, they

don't have to pay for transplant-related hospitalisation, surgery and they will be assured of life-long care."

On top of the free healthcare, the donor would be entitled to be admitted to first class at government hospitals as described by KI–2.

"There is also the donor privilege card for kidney donors to get first-class treatment at government hospitals."

b. Deceased renal transplant

i. Promoting awareness among family members to donate deceased's organs

KI–6 opined that the family member's perception against donating the deceased's organ could be solved by providing education and awareness to them.

"I suppose we need to educate them. I think that is not a big problem. It is for them to accept that the deceased has pledged and follow the desire of that person."

ii. Waive deceased's hospital bill for family members who consent for organ donation

KI–7 stated that public hospitals would waive any hospital fees accumulated by the deceased during hospitalization when the family member's consent for organ donation as a token of appreciation.

"We don't say that we incentivize, but we just say that it is one of the ways (we could) ease the burden of the family members. Once the family members have donated the deceased organ. We will waive the hospital fees."

4.2.5.3 Community-Level Factor

Themes that emerged from this factor were changing perceptions of the community, promoting organ donation and renal transplant benefits and empowering the community to be healthy.

a. Changing perceptions of the community

The perception of the society has on organ donation needs to be handled based on the dichotomy of living related and deceased separately.

i. Living-related renal transplant

KI–8 mentioned that the community needs to be educated that donating their organ is safe, and it is the most altruistic act anyone can do for their family member.

"We need to build up people's acceptance of giving their organ is very safe and does not affect their wellbeing. Giving your organ is the greatest gift given to anybody."

ii. Deceased renal transplant

KI–7 informed that the Ministry of Health continuously engaged religious authorities in Muslim communities and appointed public figures as organ donor ambassadors to encourage organ donation.

"We are actively campaigning with JAKIM[22] and also with IKIM[23] in terms of religious perspective and also giving the message to the community (about organ donation). We do have organ donation ambassadors to inspire the public."

b. Promoting organ donation and renal transplant benefits

KI–7 discussed the strategies implemented by the Ministry of Health in creating awareness for organ donation by targeting the younger generation because they are more receptive of donating their organs.

"...strategy for organ donation awareness, we have 6 strategies, so among the strategy, we have one is targeting the younger generation because we believe they're more receptive and more open towards this cause."

KI–8 lamented that many in the society were not aware of the benefits of renal transplant, which is better than dialysis and the need to disseminate that information to the public is essential.

[22] JAKIM (Jabatan Kemajuan Islam Malaysia or Department for the Advancement of Islam) coordinates interstate Islamic affairs and oversees the implementation of Islamic laws. (Shah, 2017)

[23] IKIM (Institut Kefahaman Islam Malaysia or Institute of Islamic Understanding Malaysia) provides an open and free space for everyone to share their opinion to discuss about Islam (Institut Kefahaman Islam Malaysia, 2018)

"People need to know that transplant is a better option than dialysis and its cheaper and much better quality of life and survival."

Furthermore, KI–6 provided a solution to the issue by intensifying and highlighting it in the media, so the public is exposed to renal transplantation and its benefit.

"So, we need news like this (successful renal transplantation) to be highlighted to create awareness among the public."

c. Encourage the community to be healthy to prevent diseases

KI–8 went beyond conventional norms by suggesting that patients with well-controlled health indicators would get incentives if they continued to maintain it.

".... give incentive (to the patient) when they are healthy, by reducing their annual income tax. Then they will go prove to you that their HbA1C[24] is controlled, their blood sugar is controlled, and their BMI[25] is controlled."

[24] HbA1C is a blood investigation used to detect the blood sugar level preceding 2-3 months and maybe use as a diagnostic test of diabetes mellitus (John et al., 2012)

[25] BMI denotes body mass index is obtained from weight in kilogram divided by square of height in metre. It is a proxy for thinness and fatness and has been directly related to health risks and death rates. (John et al., 2012)

4.2.5.4 Institutional-Level Factor

Under this factor, four major themes emerged; maximizing healthcare resources, centralized transplant centre, improving waiting time, continuous transplant education to healthcare providers and stakeholder's advocacy for transplant.

a. Maximizing healthcare resource

The sub-themes that emerged from healthcare resources were expertise utilization and retention, centralizing transplant centre and improving support services.

i. Expertise utilization and retention

KI–2 suggested that family physicians should be incentivised to ensure patients do not develop the end-stage renal disease (ESRD) like in the United Kingdom (UK) and to counsel them for appropriate renal replacement therapy when required.

> *"Primary care plays an important role in being the gatekeeper for renal failure patients, and they are paid to do it. For example, in the UK, the GPs[26] are the one who would manage the patients with diabetes and hypertension, ensuring that they have their annual routine examination to determine end-organ damage and to counsel and educate them about their prospects when ESRD ensues."*

[26] GPs denotes general practitioners

The experts in renal transplant who previously went into private practice could be engaged for renal transplantation in the transplant centre to fill the vacancy of expertise in the field as proposed by KI–6.

"There are probably at least about ten surgeons, nephrologists and intensivists out in the private (practice) who has experience in doing the transplant. If all of them are included, I am sure there will be enough resources."

KI–7 considered that training in renal transplantation at renowned transplant hospitals in the world would encourage surgeons to take up the sub-speciality.

"For the past few years, we sent our surgeon for kidney transplant training. The training mechanism is something like an incentive."

ii. Centralizing transplant centre for better service

KI–3 described how incorporating all the centres into one centralized transplant centre just for transplantation would improve the allocation of resource.

"Just establish one centre first (by) putting all the resources (in one place). Currently, it is split in MOH[27] between HKL[28] and Selayang[29]. Just have one centre

[27] MOH denotes Ministry of Health

[28] HKL denotes Kuala Lumpur Hospital

[29] Selayang in this context refers to Selayang Hospital

where all the resources are placed in one place in an organised department of its own."

iii. Improving supporting services to expedite screening

KI–3 described two mechanisms whereby laboratory services can be enhanced in the current setting; the formation of a transplant surgery department with the lab facilities or to use existing facilities but reforming the pathway for a shorter pre-transplant assessment.

"There is a need for a department of transplant surgery (with) immunological lab support, pharmacy support for drugs and money to buy all those drugs and all the lab services to support the workup. They can actually use existing lab facilities without creating a new lab, but they have to have a pathway that is direct, responsive and quick."

b. Improving waiting time by cooperating with other departments

KI –2 mentioned that the transplant team could coordinate with the pathology or radiology department to improve the waiting time for pre-transplant assessment.

"An understanding between the departments in HKL that allows the patients to be assessed faster, which cut down the waiting time for the cardiac assessment and for the radiological assessment."

c. Providing continuous transplant education to healthcare providers

KI–4 proposed that healthcare providers need to be continuously updated on organ donation and transplantation by collaborating with the international institutions to learn best practices.

"... organizing a sustainable program to educate the transplant fraternity. This program is a collaboration between local universities with the worlds´ leading organization in organ donation, Donation Transplantation Institute in Spain."

d. Stakeholder advocacy for transplant

KI–5 revealed that renal transplantation requires many advocates and not just the few who are currently championing it. The dissemination of information by researchers is essential to educate the fraternity on the issues faced currently.

"We need to have more champions because if we rely on one or two loud voice and these loud voice does not reach the ears that supposed to hear it. Then you will not going to solve this problem. If we just discuss it within these four walls or when you write your research thesis without disseminating it, we will continue to discuss about this for many more years to come."

Even KI–4 single out the researcher in hopes that the researcher disseminates the information.

"Dr Peter, I hope you (as a healthcare practitioner) preach the same to your friends and family about organ donation and renal transplant."

4.2.5.5 System-Level Factor

a. Persuading top management to prioritize transplant

KI–8 lamented that the final decision on funding and prioritization for renal transplantation falls to the top management and they needed to be prompted on renal transplantation's importance.

> *"...what we need is a very firm decision by the ministry of health to agree to this. It has to come from the minister downwards. The minister has to buy in. The DG[30] has to buy in."*

KI–1 echoed that policymakers need to put their foot down and stop prioritizing dialysis and look at ways to improve renal transplantation in Malaysia.

> *"These guys are policymakers, so they must be an expert in their field. They must look at the problems and say "look, guys, we are just wasting too much money on haemodialysis, the graft goes like this, the expense goes like this, it is not sustainable. How can we improve renal transplantation?"*

b. Policy reform

The heterogeneity of the healthcare system between the hospitals of the Ministry of Health and ministry of education needs to be integrated, as suggested by KI–6.

[30] DG denotes the Director General of Health in the Ministry of Health Malaysia

"The MOH policies must be inclusive of university hospitals."

KI–5 was discouraged when discussion on policy reforms because having the policy in place did not equate to the implementation of the policy. More efforts are required and needed to actualize the policy as mentioned by KI–5.

"The policy should be reflected in the affirmative step to reflect that policy. If for example, we say yes transplant is a preferred method because we believe that it is a better treatment, because it is a more effective treatment, because it is a more cost-effective treatment, then the system must be in place to reflect that."

The revision of the current law governing organ transplant has been in the pipeline, and KI–7 believed it would help improve the renal transplantations in Malaysia.

"We hope that we can table the Bill soon. That is one of our efforts we also (have) in the pipeline on how to increase the kidney transplant in Malaysia."

c. Exploring options for organ donation to improve organ donation

Most of the key-informants were opponents of the idea of implementing the opt-out system in Malaysia. Therefore, other channels of improving the organ donation and transplantation rates emerged from the in-depth interviews as an alternative to the opt-out system.

i. Deceased organ transplant

KI–6 suggested the government explore the possibility of targeting motorists as a source for organ donation because of the high road traffic accident rate in Malaysia.

"We have one of the highest rates of road traffic accident in the world, and many of them are young motorcyclists. So, these are all the potential donors that we are not tapping onto."

While KI–5 provided insight on how to implement the idea of focusing organ donation to drivers or motorists by supplementing organ donation form during license renewal.

"Everyone has to renew driving license, and when you apply for your driving license, you have to fill up your particulars all these things. Some countries actually use that opportunity to seek donation request."

ii. Living-related organ donation

KI–5 illustrated the domino effect of kidney donor chain practised by some foreign country that allows the unrelated organ donation instead of restricting it to living related only.

"When people pledge, they will cause a domino effect, the term that they use is a never-ending altruistic donation; the chain donation. For example, you come forward to give a kidney to your brother. But he cannot proceed to donation because his kidney doesn't match. But I come along and say I'm going to give the kidney to

your brother. His brother, who cannot donate to his brother (ESRD patient) will now donate to another person."

d. Include comprehensive health education and organ donation in school syllabus

The education system needs to incorporate organ donation and transplantation in their syllabus to inculcate altruism and to dispel misconception at an early age as KI–2 described optimistically.

"I think we need to look into changing the education system to be more inclusive by providing health education as well as teaching about the benefits of organ donation and addressing the stigma the community have on organ donation.

Besides organ donation and transplantation, health education and healthy lifestyle promotion should be included in schools emphasized KI–6.

"I think health education and healthy lifestyle (promotion) should be started much earlier in schools and in children that might be helpful in them later in life."

4.3 Association of Socioeconomic Status on Access to Renal Transplantation and Post-Transplant Survival

4.3.1 Summary

This sub-chapter presents the results on the association between the levels of socioeconomic status and access to renal transplantation (waiting time) and post-transplantation mortality.

ReTRAPP study found that RTRs with household income RM1000 – RM3000 and secondary educational attainment subgroups were associated with lower hazards of access to renal transplantation compared to the household income of >RM3000 and tertiary educational attainment subgroups. While RTRs who are in outside workforce subgroup was associated with higher hazards of transplantation compared to employed and unemployed RTRs. Lower household income was associated with lower hazards for access to renal transplantation.

As for the survival analyses, there was a significant association between educational attainment and post-transplantation mortality of the renal transplant recipients. Lower household income was associated with higher hazards to mortality.

4.3.2 Baseline Characteristics of Renal Transplant Recipients from National Renal Registry (2002-2011)

The subjects' background characteristics concerning socio-demographic and medical characteristics are summarized and tabulated in table 4.2 and table 4.3, respectively. It provided an understanding of the general profile and description of the subjects from the National Renal Registry.

Table 4.2: Socio-demographic characteristics of renal transplant recipients from the National Renal Registry (2002-2011)

Characteristics	Total (N)	Frequency, n (%)
Age, mean ± standard deviation	1234	42.3 ±12.3
Gender	1234	
Male		789 (63.9)
Female		445 (36.1)
Ethnicity	1226	
Chinese		797 (65.0)
Malay		287 (23.4)
Indian		110 (9.0)
Others		32 (2.6)
Employment Status	919	
Employed		640 (69.6)
Outside Workforce (retirees, homemakers, students)		229 (24.9)
Unemployed		50 (5.4)
Educational attainment	1177	
Primary		185 (15.7)
Secondary		684 (58.1)
Tertiary		308 (26.2)
Marital Status	946	
Single		258 (27.3)
Married		668 (70.6)
Others (widows, divorcees)		20 (2.1)
Household Income [#]	1140	
< RM 1000 (< USD 239)		130 (11.4)
RM 1000 – RM 3000 (USD 239 – USD 717)		630 (55.3)
> RM 3000 (>USD 717)		380 (33.3)
Geographical Location	1149	
City		681 (59.3)
Outside City		468 (40.7)

The number (%) of RTRs with missing data were 315 (25.5%) for employment status, 288 (23.3%) for marital status, 94 (7.6%) for household income, 85 (6.9%) for geographical location and 8 (0.6%) for ethnicity

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Based on table 4.2, there were 1234 RTRs between 1st January 2002 and 31st December 2011, in Malaysia. The RTRs mean age was 42.3 ±12.3 years, with the majority being male (63.9%). Majority of the RTRs are Chinese (65.0%), followed by Malay (23.4%), Indian (9.0%) and finally other ethnicities (2.6%). The Employment

status is divided into three different categories, namely the Employed (69.6%), Outside Workforce (24.9%) and lastly Unemployed (5.4%). Most of the RTRs have secondary educational level attainment (58.1%), followed by tertiary educational level attainment (26.2%) and primary educational level attainment (15.7%).

RTRs marital status was divided into singles (27.3%), married (58.1%) and others that include widowers and divorcees (2.1%). Besides that, 55.3% of the RTRs have a household income of RM 1000 – RM 3000 (USD 239 – USD 717), 33.3% with a household income of >RM 3000 (>USD 717) and 11.4% with a household income of <RM 1000 (<USD 239). Most of the RTRs reside in cities (n=681, 59.3%). Employment status (25.5%) and marital status (23.3%) were the characteristics with the most missing information from the National Renal Registry.

Table 4.3: Medical characteristics of renal transplant recipients from the National Renal Registry (2002-2011)

Characteristics	Total (N)	Frequency, n (%)
Pre-Transplantation		
Dialysis Modality	941	
Haemodialysis		862 (91.6)
Peritoneal Dialysis		79 (8.4)
Donor Type	1218	
Deceased		808 (66.3)
Living		410 (33.7)
Transplant Centre	1234	
Local		426 (34.5)
Overseas		808 (65.5)
Comorbidities		
Diabetes	941	153 (16.3)
Hypertension	941	715 (76.0)
Coronary Artery Disease	958	38 (4.0)
Cerebrovascular Disease	941	4 (0.3)
Cancer	941	4 (0.3)
Multimorbidity (≥2)	941	145 (11.8)
Smoking	921	873 (94.8)
Body Mass Index (BMI), mean ± standard deviation	1025	22.3 ± 4.34
Duration of Dialysis (months), median (IQR)	946	20.7 (10.5, 48.1)
Post-Transplantation		
Complication		
Diabetes	1234	279 (22.6)
Coronary Artery Disease	1234	50 (4.1)
Cerebrovascular Accident	1234	9 (0.7)
Cancer	1234	43 (3.5)
Multimorbidity (≥2)	1234	83 (6.7)
Body Mass Index (BMI), mean ± standard deviation	1111	28.9 ± 5.2
Survival (months), median (IQR)	1234	65.3 (36.5, 91.7)

IQR, interquartile range

The number (%) of RTRs with missing data were 293 (23.7%) for dialysis modality, diabetes, hypertension, cancer and pre-transplantation multimorbidity, 288 (23.3%) for duration of dialysis, 276 (22.4%) for coronary heart disease and cerebrovascular disease, 209 (16.9%) for pre-transplantation body mass index, 123 (10.0%) for post-transplantation body mass index and 16 (1.5%) for donor type.

Table 4.3 shows the medical characteristics of renal transplant recipients from the National Renal Registry from 2002 up until 2011. The medical characteristics of the RTRs are divided into Pre-Transplantation and Post-Transplantation. There are seven characteristics under Pre-Transplantation. The RTRs were more likely to be on haemodialysis (91.6%), undergone deceased renal transplantation (66.3%) at a transplantation centre that is overseas (65.5%). Hypertension (76.0%) and diabetes (16.3%) are the two most common co-morbid diseases suffered by the RTRs with (11.8%) of them suffering more than two chronic diseases at a time. A vast majority of the RTRs indicated that they have a history of smoking (94.8%). RTRs have an average BMI of 22.3 ± 4.34 and an average duration of dialysis of 20.7 months (interquartile range 10.5 - 48.1).

As for the Post-Transplantation, the medical characteristics involved are Complications, Body Mass Index (BMI) and survival rate in months. The RTRs reported suffering mostly from diabetes (22.6%) which was followed by coronary artery disease (4.1%) and cancer (3.5%). About 11.8% of the RTRs were reported suffering from two or more chronic diseases after their transplantation. There is a 29.6% increase in BMI post-transplantation with a mean of 28.9. The mean survival time for the RTRs is at 65.3 months (interquartile range 36.5 - 91.7)

4.3.3 Distribution of Renal Transplant Recipients Characteristics Stratified by Levels of Socioeconomic Status from National Renal Registry (2002-2011)

The data from the National Renal Registry were further stratified based on the SES indicators; educational attainment, household income and employment status. This descriptive analysis was performed to examine the patterns and distributions of each variable for the SES indicators following the research questions.

4.3.3.1 Socio-demographic Characteristics of Renal Transplant Recipients from National Renal Registry

a. Educational Attainment

Table 4.4: Socio-demographic characteristics of the renal transplant recipients by education

Characteristics	Total (N)	Educational Attainment, n (%)			P-Value
		Primary	Secondary	Tertiary	
Age, mean ± SD	1177	48.8 ± 11.9	41.2 ± 11.8	40.0 ± 12.1	**<0.001**
Gender	1177				**0.003**
Male		109 (58.9)	424 (62.0)	221 (71.8)	
Female		76 (41.1)	260 (38.0)	87 (28.2)	
Ethnicity	1169				**<0.001**
Chinese		130 (70.7)	431 (63.5)	196 (64.1)	
Malay		39 (21.2)	168 (24.7)	76 (24.8)	
Indian		10 (5.4)	63 (9.3)	27 (8.8)	
Others		5 (2.7)	17 (2.5)	7 (2.3)	
Employment Status	901				**<0.001**
Unemployed		16 (10.5)	25 (4.8)	8 (3.5)	
Outside Workforce		59 (38.8)	129 (24.7)	35 (15.5)	
Employed		77 (50.7)	369 (70.6)	183 (81.0)	
Marital status	926				**0.025**
Single		27 (29.7)	161 (29.7)	67 (28.9)	
Married		120 (78.9)	369 (68.1)	163 (70.3)	
Others		5 (3.3)	12 (2.2)	2 (0.9)	
Household Income [#]	1116				**<0.001**
< RM 1000 (< USD 239)		38 (22.0)	76 (11.7)	15 (5.1)	
RM 1000 – RM 3000 (USD 239 – USD 717)		103 (59.5)	405 (62.6)	107 (36.1)	
> RM 3000 (>USD 717)		32 (18.5)	166 (25.7)	174 (58.8)	
Geographical Location	1111				**<0.001**
City		79 (44.6)	372 (57.5)	206 (71.8)	
Outside City		98 (55.4)	275 (42.5)	81 (28.2)	

SD, standard deviation

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

The descriptive analysis is analysed using the cross-tabulation between the socio-demographic and educational attainment, an SES indicator. Table 4.4 shows the socio-demographic characteristics of renal transplant recipients by educational attainment. There are seven different socio-demographic characteristics. The mean age of primary-level educational attainment is the highest at 48.8 years, followed with secondary-level educational attainment at 41.2 years and tertiary-level educational attainment at 40.0 years.

The trend of educational level attainment for male RTRs follows the socioeconomic gradient with primary-level education attainment the lowest at 58.9% and highest at tertiary-level educational attainment at 71.8%. However, for the female RTRs, the trend of educational attainment is reversed with the highest at primary-level educational attainment (41.1%) and lowest at tertiary-level educational attainment (28.2%).

This trend of the socioeconomic gradient is also evident for employment status and household income. Whereby the employed RTRs increases with educational attainment with primary-level at 50.7%, secondary-level at 70.6% and tertiary-level at 81.0%. While the unemployed RTRs were having the opposite trend of the highest at primary-level (10.5%) and lowest at tertiary-level (3.5%). For household income, RTRs with tertiary-level educational attainment have the highest household income (58.8%) while the RTRs with primary-level educational attainment have the lowest income (22.0%). The majority of the RTRs with tertiary-level educational attainment reside in cities (71.8%) as compared to RTRs with primary-level educational attainment reside in outside of cities (55.4%).

It was noted that all the socio-demographic characteristics were statistically significant for educational attainment.

b. Household Income

Table 4.5: Socio-demographic characteristics of the renal transplant recipients by household income

Characteristics	Total (N)	Household Income, n (%) #			P-Value
		< RM 1000 (< USD 239)	RM 1000 – RM 3000 (USD 239 – USD 717)	> RM 3000 (> USD 717)	
Age, mean ± SD	1140	38.8 ± 12.2	41.1 ± 12.0	45.3 ± 12.2	**<0.001**
Gender	1140				0.062
Male		78 (60.0)	396 (62.9)	263 (69.2)	
Female		52 (40.0)	234 (37.1)	117 (30.8)	
Ethnicity	1133				**0.002**
Chinese		65 (50.4)	433 (68.9)	258 (68.8)	
Malay		42 (32.6)	134 (21.3)	79 (21.1)	
Indian		15 (11.5)	49 (7.8)	31 (8.3)	
Others		7 (5.4)	12 (1.9)	7 (1.9)	
Employment Status	886				**<0.001**
Unemployed		48 (44.9)	351 (70.6)	226 (80.1)	
Outside Workforce		41 (38.3)	122 (24.5)	51 (18.1)	
Employed		18 (16.8)	24 (4.8)	5 (1.8)	
Marital status	896				**<0.001**
Single		51 (46.8)	153 (30.4)	39 (13.7)	
Married		56 (51.4)	337 (67.0)	241 (84.9)	
Others		2 (1.8)	13 (2.6)	4 (1.4)	
Educational attainment	1116				**<0.001**
Primary		38 (29.5)	103 (16.7)	32 (8.6)	
Secondary		76 (58.9)	405 (65.9)	166 (44.6)	
Tertiary		15 (11.6)	107 (17.4)	174 (46.8)	
Geographical location	1072				**<0.001**
City		50 (39.4)	350 (58.1)	231 (67.3)	
Outside City		77 (60.6)	252 (41.9)	112 (32.7)	

SD, standard deviation

Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Table 4.5 shows the descriptive analysis by cross-tabulation between the socio-demographic and household income for renal transplant recipients from the National Renal Registry between 2002 and 2011. Based stratified household income, the mean age

of RTRs increases with a household income at <RM 1000 (38.8 years), at RM 1000 – RM 3000 (41.1 years) and >RM 3000 (45.3 years). Similar to educational attainment, male RTRs has an increasing gradient for household income. While female RTRs have the inverse gradient with highest at <RM 1000 (40%), followed by RM 1000 – RM 3000 (37.1%) and lastly > RM 3000 (30.8%). The Chinese RTRs showed a similar trend of increasing proportion with household income. However, for the other ethnicities such as Malay, Indians and Others, their household income is highest at <RM 1000.

The employment status and educational attainment show a socioeconomic gradient with the majority for the RTRs who are employed (80.1%) at the highest household income and the unemployed RTRs having the lowest household income (16.8%). While for educational attainment, the highest educational attainment earns the most household income a (46.8%) while the secondary and primary level educational attainment has the most RTRs earning <RM 1000 at (29.5%) and (16.8%) respectively. The RTRs who are married have an incremental household income from 51.4% to 67.0% and 84.9% for <RM 1000, RM 1000 – RM 3000 and > RM 3000 respectively. However, the reverse is noted for single RTRs with 46.8% earning < RM 1000, 30.4% earning RM 1000 – RM 3000 and 13.7% earning >RM 3000. Most of the RTRs living in the city earn > RM 3000 (67.3%) while RTRs living outside the city earn < RM 1000 (60.6%).

The socio-demographic characteristics that were significantly significant with household income are age, ethnicity, employment status, marital status, educational status and geographical location.

c. Employment Status

Table 4.6: Socio-demographic characteristics of the renal transplant recipients by employment status

Characteristics	Total (N)	Employment Status, n (%)			P-Value
		Unemployed	Outside Workforce	Employed	
Age, mean ± SD	919	35.0 ± 10.8	43.7 ± 14.1	42.1 ± 11.6	**<0.001**
Gender	919				**<0.001**
Male		37 (74.0)	71 (31.0)	467 (73.0)	
Female		13 (26.0)	158 (69.0)	173(27.0)	
Ethnicity	914				**0.036**
Chinese		33 (67.3)	142 (62.6)	403 (63.5)	
Malay		9 (18.4)	64 (28.2)	157 (24.7)	
Indian		3 (6.1)	12 (5.2)	62 (9.8)	
Others		4 (8.2)	9 (4.0)	13 (2.0)	
Household Income [#]	886				**<0.001**
< RM 1000 (< USD 239)		18 (38.3)	41 (19.2)	48 (7.7)	
RM 1000 – RM 3000 (USD 239 – USD 717)		24 (51.1)	122 (57.0)	351 (56.2)	
> RM 3000 (>USD 717)		5 (10.6)	51 (23.8)	226 (36.1)	
Marital Status	845				**<0.001**
Single		26 (55.3)	47 (22.3)	157 (26.7)	
Married		18 (38.3)	159 (75.4)	420 (71.6)	
Others		3 (6.4)	5 (2.4)	10 (1.7)	
Educational attainment	901				**<0.001**
Primary		16 (32.7)	59 (26.5)	77 (12.2)	
Secondary		25 (51.0)	129 (57.8)	369 (58.7)	
Tertiary		8 (16.3)	35 (15.7)	183 (29.1)	
Geographical location	894				0.092
City		23 (48.9)	118 (53.4)	337 (60.2)	
Outside City		24 (51.1)	103 (46.6)	249 (39.8)	

SD, standard deviation

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Table 4.7 shows the socio-demographic characteristics of the renal transplant recipients by employment status, which is further categorized into the unemployed, outside workforce and employed. The RTRs who are outside the workforce consists of retirees, homemakers and students. The mean age of the RTRs for the unemployed, outside workforce and employed are 35 years, 43.7 years and 42.1 years respectively. RTRs who are males dominate the unemployed subgroup (74.0%) and employed subgroup (73.0%), but, female RTRs make the majority in the outside workforce with 69%. Distribution among the ethnic groups of Chinese, Malay, Indian and Others are almost similar across the employment status spectrum. As expected, the lowest household income bracket (<RM 1000) has a reduction in the proportion of RTRs from unemployed to outside workforce and lastly to employed subgroups with 38.3%, 19.2%, and 7.7% respectively. However, the highest income bracket (>RM 3000) indicated an increase in the proportion of RTRs at 10.6%, 23.8% and 36.1% for the unemployed, outside workforce and employed subgroups respectively.

There were more RTRs who are single that are unemployed (55.3%) compared to employed RTRs (12.2%), which is similar to RTRs in others (widows and divorcees) at 6.4% for unemployed and 1.7% for employed subgroups. As for educational attainment, secondary-level and tertiary-level saw an increase in the proportion of RTRs across the employment status gradient. The primary-level demonstrated the reverse with 32.7% for unemployed RTRs, 22.3% for outside workforce RTRs and 12.2% for employed RTRs. Lastly, for RTRs who are living in cities, it is incremental from unemployed (48.9%), outside workforce (53.4%) and employed (60.2%).

Age, gender, ethnicity, marital status, household income, educational attainment are socio-demographic characteristics that were statistically significant with employment status.

4.3.3.2 Medical Characteristics of Renal Transplant Recipients from National Renal Registry

a. Household Income

Table 4.7: Medical characteristics of renal transplant recipients by educational attainment

Characteristics	Total (N)	Education, n (%)			P-Value
		Primary	Secondary	Tertiary	
Pre-Transplantation					
Dialysis modality	922				0.118
Haemodialysis		143 (94.7)	495 (91.8)	206 (88.8)	
Peritoneal Dialysis		8 (5.3)	44 (8.2)	26 (11.2)	
Donor type	1177				**<0.001**
Deceased		154 (83.2)	453 (66.8)	173 (57.7)	
Living		31 (16.8)	225 (33.2)	127 (42.3)	
Transplant Centre	1177				**<0.001**
Local		44 (23.8)	266 (38.9)	100 (32.5)	
Overseas		141 (76.2)	418 (61.1)	208 (67.5)	
Comorbidities					
Diabetes	1177	36 (19.5)	69 (10.1)	43 (14.0)	**0.002**
Hypertension	1177	117 (63.2)	408 (59.6)	174 (56.5)	0.853
Coronary Heart Disease	938	10 (5.4)	20 (2.9)	9 (2.6)	0.142
Cerebrovascular Disease	956	0 (0)	3 (0.4)	1 (0.3)	0.655
Cancer	956	2 (1.1)	2 (0.3)	0 (0)	0.147
Multimorbidity (>2)	922	34 (18.4)	63 (9.2)	43 (14.0)	**0.001**
Smoking	1177	45(24.3)	147 (21.5)	43 (14.0)	0.227
Body Mass Index (BMI), mean ± SD	1177	22.3 ± 3.8	22.1 ± 4.2	22.7 ± 4.9	0.227
Duration of Dialysis (months), median (IQR)	900	23.1 (11.4, 47.7)	21.0 (11.1, 47.7)	18.4 (8.8, 47.4)	0.388
Post-Transplantation					
Complication					
Diabetes	1177	66 (35.7)	227 (33.2)	75 (24.4)	**0.008**
Coronary Heart Disease	1177	25 (13.5)	68 (9.9)	23 (7.5)	0.092
Cerebrovascular Disease	1177	2 (1.1)	7 (1.0)	2 (0.6)	0.830
Cancer	1177	11 (5.9)	20 (2.9)	6 (1.9)	**0.042**
Multimorbidity (>2)	1177	20 (10.8)	47 (6.9)	13 (4.2)	**0.019**
Body Mass Index (BMI), mean ± SD	1177	24.7 ± 4.7	24.8 ± 5.0	25.1 ± 5.9	0.606
Survival (months), mean ± SD	1177	111.2 ± 55.2	110.9 ± 455.2	110.2 ± 43.8	0.964

SD, standard deviation; IQR, interquartile range

For the Pre-Transplantation characteristics in Table 4.7, dialysis modality that is most utilised by the RTRs is haemodialysis with the highest for primary-level educational attainment (94.7%) and decreasing to 88.8% for tertiary-level educational attainment. However, for peritoneal dialysis, the trend increases with higher educational attainment with primary, secondary and tertiary level t 5.3%, 8.3% and 11.2% respectively. The history of smoking is also prominent in lower educational attainment with primary-level having 24.2%, secondary-level at 21.5% and tertiary-level at 14.0%. The mean BMI for RTRs before transplantation is almost similar among the educational attainment; primary level (22.3 ± 3.8), secondary level (22.1 ± 4.2) and tertiary level (22.7 ± 4.9).

For Post-Transplantation, the complications of the chronic disease reported from the National Renal Registry demonstrated that lower educational attainment was more prone to chronic disease. The proportions were highest for diabetes (35.7%), coronary artery disease (13.5%), cerebrovascular disease (1.1%), cancer (5.9%) and multimorbidity of two or more chronic diseases (10.8%) in primary level. However, the mean survival time (months) shows that the primary-level educational attainment has the highest survival time with 111.2 months, followed by secondary-level educational attainment with 110.9 months and finally the tertiary educational level attainment at 110.2 months. The BMI of the RTRs has increases post-transplantation with the highest in tertiary-level educational attainment at 25.1, followed by secondary-level educational attainment at 24.8 and ultimately primary-level educational attainment at 24.7.

Donor type, transplant centre, diabetes and multimorbidity as comorbid, diabetes, cancer and multimorbidity as a complication and mean survival was medical characteristics that were statistically significant for educational attainment.

b. Household Income

Table 4.8: Medical characteristics of renal transplant recipients by household income

Characteristics	Total (N)	Household Income, n (%) [#]			P-Value
		< RM 1000 (< USD 239)	RM 1000 – RM 3000 (USD 239 – USD 717)	> RM 3000 (>USD 717)	
Pre-Transplantation					
Dialysis modality	892				0.811
Haemodialysis		98 (89.9)	460 (91.8)	258 (91.5)	
Peritoneal Dialysis		11 (10.1)	41 (8.2)	24 (6.3)	
Donor type	1127				**<0.001**
Deceased		88 (68.2)	447 (71.2)	219 (59.2)	
Living		41 (31.8)	181 (28.8)	151 (40.8)	
Transplant Centre	1140				**<0.001**
Local		66 (50.8)	206 (32.7)	107 (28.2)	
Overseas		64 (49.2)	424 (67.3)	273 (71.8)	
Comorbidities					
Diabetes	892	16 (12.3)	62 (9.8)	72 (18.9)	**<0.001**
Hypertension	892	84 (64.6)	371 (74.1)	227 (58.7)	0.123
Coronary Heart Disease	906	3 (2.3)	19 (3.0)	16 (4.2)	0.385
Cerebrovascular Disease	889	0 (0)	2 (0.3)	2 (0.5)	0.623
Cancer	892	0 (0)	2 (0.3)	2 (0.5)	0.623
Multimorbidity (>2)	892	17 (13.1)	54 (8.6)	72 (18.9)	**<0.001**
Smoking	877	26 (20.0)	135 (21.4)	65 (17.1)	0.510
Body Mass Index (BMI), mean ± SD	1140	21.4 ± 4.4	22.0 ± 4.0	23.3 ± 4.8	**<0.001**
Duration of dialysis (months), median (IQR)	868	21.0 (9.8, 45.1)	22.3 (11.4, 55.3)	18.9 (9.2, 43.5)	0.151
Post-Transplantation					
Complication					
Diabetes	1140	39 (30.0)	185 (29.4)	138 (36.3)	0.064
Coronary Heart Disease	1140	12 (9.2)	53 (8.4)	50 (13.2)	**0.050**
Cerebrovascular Disease	1140	0 (0)	5 (0.8)	6 (1.6)	0.228
Cancer	1140	5 (3.8)	19 (3.0)	12 (3.2)	0.886
Multimorbidity (>2)	1140	7 (5.4)	40 (6.3)	32 (8.4)	0.346
Body Mass Index (BMI), mean ± SD	1140	24.3 ± 5.0	24.8 ± 5.1	25.4 ± 5.6	0.110
Survival (months) mean ± SD	1140	104.5 ± 48.7	106.7 ± 52.6	114.2 ± 48.9	0.052

SD, standard deviation; IQR, interquartile range

[#] Conversion rate, RM 1 = USD 0.239 (Bank Negara Malaysia, 2019)

Table 4.8 shows the medical characteristics of renal transplant recipients by household income which is divided into Pre-Transplantation and Post-Transplantation. Under Pre-Transplantation, the dialysis modality based on household income indicate that RTRs with higher income prefer haemodialysis with earning of RM 1000 – RM 3000 at 91.8% and > RM 3000 at 91.5%. While for peritoneal dialysis has a steady incremental as the household income reduces. RTRs at the lower household income brackets were more inclined to deceased renal transplantation at 68.2% for <RM 1000 and 71.2% for RM 1000 – RM 3000 compared to highest household income earner with almost equal deceased (59.2%) and living renal transplantations. RTRs with the lowest household income have an equal opportunity to undergone transplantation at a local and overseas transplant centre. However, the RTRs in higher household income brackets, RM 1000 – RM 3000 (67.3%) and >RM 3000 (71.8%) were more likely to transplant overseas. The mean BMI of the RTRs shows a rise with increasing household income of <RM1000, RM 1000 – RM 3000 and > RM 3000 at 21.4, 22.0 and 23.3 respectively.

Under Post-Transplantation, the complications of diabetes, coronary heart disease, cancer and multimorbidity afflict the RTRs in the lowest (<RM 1000) and highest (>RM 3000) household income subgroups more compared to the intermediate household income (RM 1000 – RM 3000). The mean BMI of the RTRs shows an increment compared to pre-transplantation with a similar socioeconomic trend of 24.3, 24.8 and 25.4 for household income < RM 1000, RM 1000 – RM 3000 and > RM 3000 respectively.

Medical characteristics that showed statistical significance for household income were donor type, transplant centre, diabetes as a comorbid, smoking, pre-transplant BMI and coronary heart disease as a complication.

c. Employment Status

Table 4.9: Medical characteristics of renal transplant recipients by employment status

Characteristics	Total (N)	Employment Status, n (%)			P-Value
		Unemployed	Outside Workforce	Employed	
Pre-Transplantation					
Dialysis modality	848				0.252
Haemodialysis		44 (91.7)	187 (88.6)	544 (92.4)	
Peritoneal Dialysis		4 (8.3)	24 (11.4)	45 (7.6)	
Donor type	910				0.416
Deceased		37 (74.0)	162 (71.3)	430 (67.8)	
Living		13 (26.0)	64 (28.3)	204 (32.2)	
Transplant Centre	919				0.868
Local		20 (40.0)	84 (36.7)	232 (36.3)	
Overseas		30 (60.0)	145 (63.3)	408 (63.7)	
Comorbidities					
Diabetes	848	7 (14.0)	29 (12.7)	98 (16.6)	0.596
Hypertension	848	35 (70.0)	157 (68.6)	461 (72.0)	0.409
Coronary Heart Disease	865	4 (8.0)	8 (3.5)	20 (3.1)	0.382
Cerebrovascular Disease	848	2 (4.0)	1 (0.4)	2 (0.3)	0.878
Cancer	848	0 (0)	3 (1.3)	0 (0)	**0.011**
Multimorbidity (>2)	848	6 (12.0)	26 (11.4)	94 (14.7)	0.397
Smoking	873	20 (40.0)	22 (9.6)	167 (26.1)	**<0.001**
Body Mass Index (BMI), mean ± SD	919	20.8 ± 3.9	21.1 ± 3.9	22.7 ± 4.4	**<0.001**
Duration of Dialysis (months), median (IQR)	695	29.9 (13.1, 85.6)	21.6 (10.8, 41.6)	20.8 (10.3, 50.9)	0.148
Post-Transplantation					
Complication					
Diabetes	919	11 (22.0)	63 (27.5)	211 (33.0)	0.113
Coronary Heart Disease	919	2 (4.0)	28 (12.2)	65 (10.2)	0.215
Cerebrovascular Disease	919	0 (0)	2 (0.9)	5 (0.8)	0.809
Cancer	919	1 (2.0)	12 (5.2)	21 (3.3)	0.325
Multimorbidity (>2)	919	1 (2.0)	20 (8.7)	44 (6.9)	0.228
Body Mass Index (BMI), mean ± SD	919	23.9 ± 4.3	24.3 ± 5.2	25.2 ± 5.3	**0.030**
Survival (months), mean ± SD	919	111.7 ± 49.9	110.3 ± 51.0	112.0 ± 48.5	0.906

SD, standard deviation; IQR, interquartile range

Table 4.9 shows the medical characteristics of renal transplant recipients by employment status. Although haemodialysis is the most common dialysis modality, the RTRs who are outside workforce (11.4%) have a higher percentage who undergo peritoneal dialysis compared to RTRs who are unemployed (8.3%) and employed (7.6%). The employed RTRs (32.2%) have a higher proportion undergoing living renal transplantation compared to unemployed (26.0%) and outside workforce subgroup (28.3%). Smoking is much higher for the unemployed RTRs (40%) compared to the other groups. For chronic diseases, RTRs who are outside the workforce were the only ones suffering from cancer (1.3%). The BMI of the RTRs increases from unemployed, outside workforce and employed subgroups at 20.8, 21.1 and 22.7 respectively.

For post-transplantation complications, RTRs who are in the outside workforce and employed subgroups were more common to suffer from diabetes, coronary heart disease, cerebrovascular disease, cancer and multimorbidity compared to unemployed RTRs. The BMI follows the socioeconomic gradient with employed RTRs having the highest BMI at 25.2, followed by RTRs outside workforce at 24.3 and lastly unemployed RTRs at 23.9.

Medical characteristics that showed statistical significance for employment status were cancer as comorbid, smoking, pre-transplant BMI and post-transplant BMI.

4.3.4 Distribution of Waiting Time to Transplantation by Levels of Socioeconomic Status

Table 4.10: 50th, 25th and 10th percentile for renal transplantation waiting time by socioeconomic status

SES characteristics		50th percentile (months)	25th percentile (months)	10th percentile (months)	P-Value
Educational Attainment	Primary	22.4	11.6	6.0	**<0.001**
	Secondary	22.4	11.6	6.0	
	Tertiary	16.7	8.4	4.8	
Household Income #	< RM 1000 (< USD 239)	19.2	9.5	5.0	**<0.001**
	RM 1000 – RM 3000 (USD 239 – USD 717)	24.1	12.4	6.3	
	> RM 3000 (> USD 717)	17.0	8.4	5.1	
Employment Status	Unemployed	31.8	16.0	8.8	**<0.001**
	Outside Workforce	19.6	10.7	5.5	
	Employed	20.7	10.0	5.4	

SE, Standard Error

Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Table 4.10 shows the 50th, 25th and 10th percentile of renal transplantation waiting time by socioeconomic status. All the socioeconomic characteristics were associated with the waiting time for renal transplantation (P<0.001).

For education attainment, RTRs with primary and secondary education attainment have longer waiting time to transplantation compared to RTRs with tertiary education attainment. While for RTRs earning >RM 3000 has the lowest median waiting time compared to the other household income levels. Finally, the unemployed RTRs have the highest median waiting time compared to those who are employed and outside workforce.

4.3.5 Association between Levels of Socioeconomic Status and Access to Renal Transplantation

Table 4.11: Association of socioeconomic status and waiting time to renal transplantation

Characteristics	Univariable Analysis Cox Analyses		Multivariable Analysis Cox Analyses[1]	
	Hazard Ratio (95% CI)	P-Value	Hazard Ratio (95% CI)	P-Value
Educational Attainment[a]				
Tertiary	1 (reference)		1 (reference)	
Secondary	0.77 (0.66, 0.91)	**0.002**	0.79 (0.67, 0.93)	**0.006**
Primary	0.95 (0.77, 1.17)	0.611	1.00 (0.80, 1.25)	1.000
Trend for P-Value		0.240		0.474
Household income[b, #]				
> RM 3000 (> USD 717)	1 (reference)		1 (reference)	
RM 1000 – RM 3000 (USD 239 – USD 717)	0.73 (0.63, 0.84)	**<0.001**	0.67 (0.58, 0.79)	**<0.001**
< RM 1000 (< USD 239)	0.88 (0.69, 1.13)	0.320	0.80 (0.62, 1.04)	0.098
Trend for P-Value		**0.011**		**0.001**
Employment[c]				
Employed	1 (reference)		1 (reference)	
Outside Workforce^	1.35 (1.14, 1.60)	**0.001**	1.45 (1.21, 1.75)	**<0.001**
Unemployed	0.93 (0.69, 1.25)	0.632	0.90 (0.65, 1.25)	0.522
Trend for P-Value		0.105		0.089

CI, confidence interval

[1a] Adjusted for age, gender, ethnicity and geographical location

[1b] Adjusted for age, gender, ethnicity, geographical location and employment status

[1c] Adjusted for age, gender, ethnicity, geographical location and educational level attainment

[#] Exchange rate, RM 1 = USD 0.239 (Bank Negara Malaysia, 2019)

[^] Outside workforce; retirees, homemakers, students

The associations between SES and access to renal transplantation were modelled using Cox Proportional Hazards – Regression Model. Table 4.11 summarizes the crude and adjusted associations between levels of SES and waiting time to renal transplantation. RTRs with secondary educational attainment 21% (adjusted HR = 0.79, 95%CI: [0.67, 0.93]) had a lower hazard of transplantation compared to RTRs with tertiary or primary educational attainment.

Compared to RTRs with household income of >RM3000, those with household income of < RM 1000 and RM 1000 – RM 3000 had 20% (adjusted HR – 0.80, 95%Cl: [0.63, 1.04]) and 33% (adjusted HR = 0.67, 95%CI: [0.58, 0.79]) lower hazards of transplantation respectively. RTRs who were outside the workforce had 45% higher hazards of transplantation compared to those who were employed (adjusted HR = 1.45, 95%CI: [1.21, 1.75]). Lower levels of household income were associated with lower hazards of transplantation (adjusted P_{Trend} = 0.001). The association between access to renal transplantation and educational attainment and employment status did not achieve statistical significance.

Socioeconomic Status Characteristics	Adjusted HR (95% CI)	P-Value	P-Trend
Educational Attainment			0.474
Tertiary	1.0 (reference)		
Secondary	0.79 (0.67, 0.93)	**0.006**	
Primary	1.00 (0.80, 1.25)	1.000	
Household Income			**0.001**
RM 3,000 (>USD 717)	1.0 (reference)		
RM 1,000 – RM 3,000 (USD 239 – USD 717)	0.67 (0.58, 0.79)	**<0.001**	
< RM 1000 (< USD 239)	0.80 (0.62, 1.04)	0.098	
Employment Status			0.089
Employed	1.0 (reference)		
Outside Workforce	1.45 (1.21, 1.75)	**<0.001**	
Unemployed	0.90 (0.65, 1.25)	0.522	

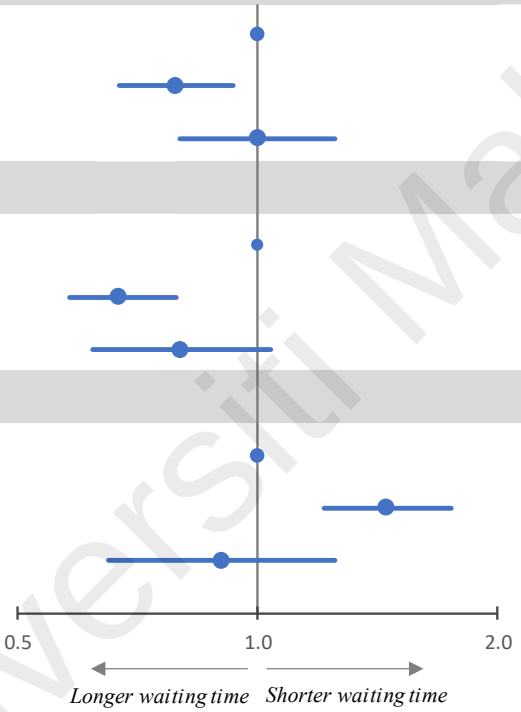


Figure 4.2: Adjusted association between socioeconomic characteristics and waiting time for renal transplantation

Figure 4.3 shows the association of SES indicators (namely educational attainment, household income and employment status) with access to renal transplantation. The trend for P-Value, which is a test for linearity shows a significance (P<0.001) for household income only; however, from the figure, the association appears to be non-linear.

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

4.3.6 Distribution of Renal Transplant Recipients Survival by Levels of Socioeconomic Status

Table 4.12: 75th percentile for renal transplantation survival by socioeconomic status

SES characteristics		75th percentile (months)	P-Value
Educational Attainment	Primary	155	**<0.001**
	Secondary	148	
	Tertiary	146	
Household Income #	< RM 1000 (< USD 239)	149	**<0.001**
	RM 1000 – RM 3000 (USD 239 – USD 717)	152	
	> RM 3000 (> USD 717)	143	
Employment Status	Unemployed	147	**<0.001**
	Outside Workforce	149	
	Employed	148	

SE, Standard Error

Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Table 4.12 shows the 75th percentiles of survival times following renal transplantation stratified by socioeconomic status. The 75th percentile was selected because the survival times did not fall below the 65th percentile. Therefore, the median survival times are undefined. All the socioeconomic characteristics were associated with the survival of renal transplantation (P<0.001).

4.3.7 Association between Levels of Socioeconomic Status and Post-Transplantation Mortality

Table 4.13: Association of socioeconomic status and post-transplantation mortality

Characteristics	Univariable Analysis Cox Analyses		Multivariable Analysis Cox Analyses[1]	
	Hazard Ratio (95% CI)	P-Value	Hazard Ratio (95% CI)	P-Value
Educational attainment[a]				
Tertiary	1 (reference)		1 (reference)	
Secondary	1.55 (1.52, 3.01)	**0.004**	1.69 (1.38, 2.31)	**0.001**
Primary	2.15 (1.52, 3.05)	**<0.001**	2.02 (1.38, 3.00)	**<0.001**
Trend for P-Value		**<0.001**		**<0.001**
Household income[b, #]				
> RM 3000 (> USD 717)	1 (reference)		1 (reference)	
RM 1000 – RM 3000 (USD 239 – USD 717)	1.01 (0.79, 1.30)	0.913	1.23 (0.94, 1.60)	0.128
< RM 1000 (< USD 239)	1.25 (0.87, 1.79)	0.236	1.42 (0.95, 2.10)	0.085
Trend for P-Value		0.341		0.056
Employment[c]				
Employed	1 (reference)		1 (reference)	
Outside Workforce [^]	1.14 (0.87, 1.5)	0.705	1.25 (0.91, 1.70)	0.165
Unemployed	0.90 (0.51, 1.57)	0.340	1.15 (0.64, 2.07)	0.646
Trend for P-Value		0.722		0.215

CI, confidence interval

[1a] Adjusted for age, gender, ethnicity and geographical location

[1b] Adjusted for age, gender, ethnicity, geographical location and employment status

[1c] Adjusted for age, gender, ethnicity, geographical location and educational level attainment

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

[^] Outside workforce; retirees, homemakers, students

Table 4.13 summarised the crude and adjusted association between levels of socioeconomic status and hazard of mortality. Lower education attainment was associated with higher hazards of mortality (adjusted P_{Trend} = 0.001). Compared to RTRs with tertiary educational attainment, RTRs with secondary and primary educational attainment had 69% (adjusted HR 1.69, 95%CI 1.38, 2.31) and 102% (adjusted HR 2.02, 95%CI 1.38, 3.00) higher hazards of mortality, respectively. The association between post-transplantation mortality and household income and employment status did not achieve statistical significance.

Socioeconomic Status Characteristics	Adjusted HR (95% CI)	P-Value	P-Trend
Educational Attainment			**<0.001**
Tertiary	1.0 (reference)		
Secondary	1.69 (1.38, 2.31)	**0.001**	
Primary	2.02 (1.38, 3.00)	**<0.001**	
Household Income			0.056
> RM 3000 (> USD 717)	1.0 (reference)		
RM 1,000 – RM 3,000 (USD 239 – USD 717)	1.23 (0.94, 1.60)	0.128	
< RM 1,000 (< USD 239)	1.42 (0.95, 2.10)	0.085	
Employment Status			0.215
Employed	1.0 (reference)		
Outside Workforce	1.25 (0.91, 1.70)	0.165	
Unemployed	1.15 (0.64, 2.07)	0.646	

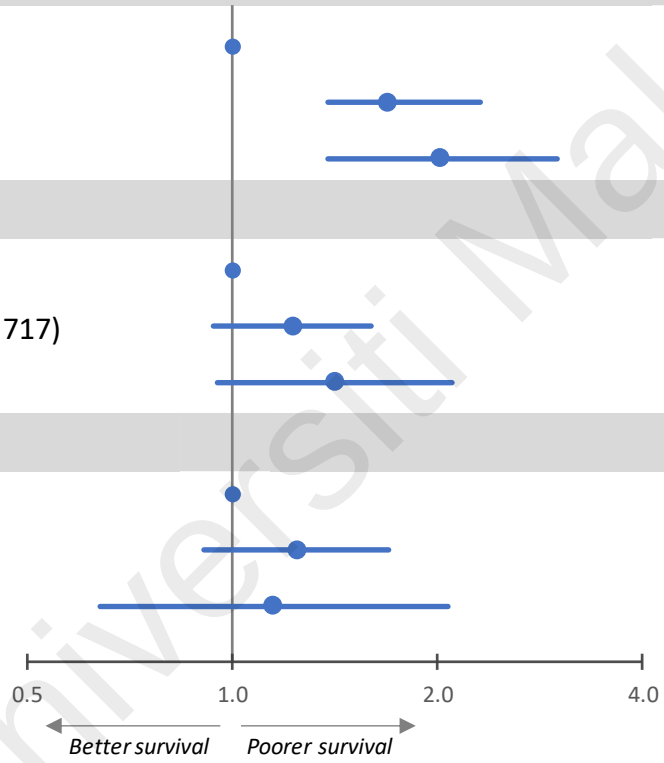


Figure 4.3: Adjusted associations between socioeconomic characteristics and post-transplantation mortality

Figure 4.5 shows the association of SES indicators (namely educational attainment, household income and employment status) with renal post-transplantation survival. The trend for P-Value, which is a test for linearity shows a significant difference (P<0.001) for educational attainment.

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

4.4 Association of Socioeconomic Status on Post-Transplantation Quality of Life and Financial Burden

4.4.1 Summary

This sub-chapter summarizes the results of the associations of quality of life (QOL) and the financial burden with levels of SES in renal transplant recipients (RTRs). This sub-chapter answers objective 4 and 5 or ReTRAPP.

ReTRAPP study found that the lower the levels of educational attainment and household income, the lower the scores of WHOQOL physical, psychological, social and environmental domains as well as the overall QOL. While the lower the levels of employment status, only WHOQOL physical and social domains shows a lower score of WHOQOL.

As for the prevalence of financial burden, there was a significant association between household income and prevalence of catastrophic health expenditure of renal transplant recipients. Lower levels of household income were associated with increased risks of catastrophic health expenditure for post-transplantation care.

4.4.2 Study Population Characteristics

A total of 409 renal transplant recipients (RTRs) were recruited for the survey on quality of life in ReTRAPP study. Table 4.14. shows the distribution of the RTRs by public hospitals in the Greater Kuala Lumpur area.

Table 4.14: Distribution of Renal Transplant Recipients by hospitals

Hospital	Frequency, n (%)
Kuala Lumpur Hospital	168 (41.1)
Selayang Hospital	79 (19.3)
Serdang Hospital	20 (4.9)
Tengku Ampuan Rahimah Hospital	20 (4.9)
Universiti Malaya Medical Centre	85 (20.8)
Universiti Kebangsaan Malaysia Medical Centre	37 (9.0)
Total	**409 (100.0)**

4.4.3 Baseline Characteristics of RTRs by Primary Data Collection

The subjects' background characteristics concerning socio-demographic, medical and financial characteristics are summarized and tabulated in Table 4.15, Table 4.16 and Table 4.17, respectively. It provided an understanding of the general profile and description of the subjects from the survey conducted.

Table 4.15: Socio-demographics characteristics of Renal Transplant Recipients

Socio-Demographic Characteristics	Total (N)	Frequency, n (%)
Age, Mean ± Standard Deviation	409	47.2 (±14.2)
Gender	409	
Male		229 (56.0)
Female		180 (44.0)
Ethnicity	409	
Malay		130 (31.8)
Chinese		228 (55.7)
Indian		42 (10.3)
Others		9 (2.2)
Educational Attainment	409	
No Education / Primary		61 (14.9)
Secondary		163 (39.9)
Tertiary		185 (45.2)
Employment	409	
Unemployed		44 (10.8)
Outside Workforce (retirees, homemakers, students)		109 (26.7)
Employed		256 (62.5)
Employment Sector	409	
Public		44 (10.8)
Private		143 (35.0)
Self-employed		86 (21.0)
Unemployed		136 (33.3)
Marital Status	409	
Single		117 (28.6)
Married		270 (66.0)
Others (widows, divorcees)		22 (5.4)
Geographical Location	408	
Greater Kuala Lumpur		295 (72.3)
Others		113 (27.7)

The number (%) of RTRs with missing data was 1 (0.2%) for the geographical location

Based on Table 4.15, there were 409 RTRs who have participated in the survey. Out of the 409 RTRs who were recruited during the study period, only 1 (0.2%) RTR did not complete the survey. The RTRs mean age was 47.2 years, with the majority of the RTRs being male (56.0%). The Chinese are the majority of the RTRs participants at 55.7%, followed by Malay (31.8%), Indian (10.3%) and others (2.2%). Educational attainment

by the RTRs is divided into primary-level (14.9%), secondary-level (39.9%) and tertiary-level (45.2%).

Most of the RTRs are employed with 62.5%, and RTRs outside the workforce make up 26.7% and unemployed RTRs at (10.8%). From the survey, the majority of the participants were from the private sector (35%) and from sectors that were unable to be categories (33.3%). Married RTRs made up the majority of the participants with 66.0%, followed by single RTRs at 28.6% and finally Others (widows and divorcees) with 5.4%. The RTRs were predominantly residing in the Great Kuala Lumpur area (72.3%).

Table 4.16: Medical Characteristics of Renal Transplant Recipients

Medical Characteristics	Total (N)	Frequency, n (%)
Pre-Transplantation		
Donor type	408	
Living		255 (62.3)
Deceased		153 (37.4)
Transplant Centre	408	
Local		248 (60.6)
Overseas		160 (39.1)
Perceived preparedness for transplant[1]	409	
Physical		379 (92.7)
Emotional		374 (91.4)
Spiritual		377 (92.2)
Financial		322 (78.7)
Duration of Dialysis (months), Median (IQR)	407	12 (5.0, 36.0)
Post-Transplantation		
Follow-up Compliance	409	347 (84.8)
Medication Compliance	409	399 (97.6)
Duration Since Transplant (months), Median (IQR)	407	108 (48.0, 168.0)
Comorbidities[1]	409	
Diabetes		99 (24.2)
Hypertension		260 (63.6)
Coronary Heart Disease		37 (9.0)
Cerebrovascular Disease		9 (2.2)
Cancer		5 (1.2)
Multimorbidity (>2)		94 (23.0)
Healthcare Provider	409	
Ministry of Health		287 (70.2)
Ministry of Education		122 (29.8)

The number (%) of RTRs with missing data were 2 (0.5%) for the duration of dialysis and duration since transplant and 1 (0.2%) for donor type and transplant centre

[1] The comorbidities and perceived preparedness are questions with multiple choice for RTRs to select yes or no

Table 4.16 shows the medical characteristics of the RTRs who participate in the survey. The characteristics are divided into Pre-Transplantation and Post-Transplantation. Most of the RTRs have undergone living renal transplantation (62.3%) and performed in a local transplant centre (60.6%). Majority of the RTRs have very high perceived preparedness for the renal transplantation above 90% for physical, emotional and

spiritual. However, their perceived financial prepared is much lower at 78.7% compared to the other preparedness. The median duration of dialysis for the RTRs is 12 months.

Under Post-Transplantation, the compliance of the RTRs to the regular out-patient follow-ups was 84.8% and for medication was 97.6%. The median duration post-transplantation for the RTRs is 108 months (interquartile range 5.0-36.0). Hypertension was the prevalent comorbid disease most common amongst the RTRs at 63.6%, and this was followed by diabetes (24.2%). There are 23% of the RTRs who suffers from two or more chronic disease from the survey. The study population frequently seek care from facilities provided by the Ministry of Health (70.2%) compared to the Ministry of Education (29.8%).

Table 4.17: Financial Characteristics of Renal Transplant Recipients

Financial Characteristics	Total (N)	Frequency, n (%)
Household Income[1, #]	398	
Bottom 40% (<RM4360)		152 (38.2)
Middle 40% (RM4360–RM9619)		145 (36.4)
Top 20% (>RM9619)		101 (25.4)
Out-of-pocket Payment[2]	408	
Current income		242 (61.5)
Savings		141 (34.6)
Bank Loan		9 (2.2)
Family/Friend Loan		32 (7.8)
Selling Assets		18 (4.4)
Reduce Household Spending		78 (19.4)
Public Financing[2]	408	
Free healthcare		68 (16.7)
Community Welfare Department		14 (3.4)
Zakat[+]		2 (0.5)
Baitulmal[^]		5 (1.2)
Private Financing[2]	408	
Employee Insurance		26 (6.4)
Private Healthcare Insurance		26 (6.4)
Employee Provident Fund (EPF)		22 (5.6)
Social Security Organization (SOCSO)		7 (1.7)
Non-Governmental Organizations (NGO)		7 (1.7)
Perceived financial burden to health expenditure	407	
A Little		213 (52.3)
Moderate		142 (34.9)
Extreme		52 (12.8)

The number (%) of RTRs with missing data were 11 (2.6%) for household income, 2 (0.5%) for the perceived financial burden to health expenditure and 1 (0.2%) for out of pocket payment, public financing and private financing

[+] Islamic social welfare system

[^] Public institution and trustee group that handles Islamic finance

[1] Household income classified as Bottom 40%, <RM4360 (< USD 1042.04); Middle 40%, RM4360–RM9619 (USD 1042.04 – USD 2298.94); Top 20%, >RM9619 (> USD 2298.94)

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

[2] Out of pocket payment, public financing and private financing are questions with multiple choice for RTRs to select

The financial characteristics of RTRs from the survey are tabulated in Table 4.17. The household income is indicated an inverse trend with the Bottom 40% (<RM4360) at 38.2%, Middle 40% (RM 4360 – RM 9619) at 36.4% and lastly Top 20% (>RM 9619) at 25.4%. The out-of-pocket payment options that are common among the RTRs are using current income (61.5%), using their savings (34.6%) and reducing household spending (19.4%). There were 11 (2.6%) RTRs who participated in the survey but refused disclosure of their household and personal income.

Majority of the RTRs who uses public financing for the post-transplantation care received free healthcare (16.7%), either because they are government employees, family members of government employees, students or elderly. For RTRs who financial their post-transplantation care via private financing mainly utilized their employee insurance (6.4%), their personal healthcare insurance (6.4%) or their EPF savings (5.6%). 52.3% of the RTRs felt that the financial burden of post-transplantation care was minimal, 34.9% of the RTRs felt it was moderate, and 12.8% felt extremely burdened.

4.4.4 Distribution of Renal Transplant Recipients Characteristics Stratified by Levels of Socioeconomic Status

The data from the Survey conducted by the Researcher were further stratified based on the SES indicators; educational attainment, household income and employment status. This descriptive analysis was performed to examine the patterns and distributions of each variable for the SES indicators following the research questions.

4.4.4.1 Educational Attainment

a. Socio-demographic Characteristics of Renal Transplantation Recipients by Educational Attainment from Survey

Table 4.18: Socio-demographic characteristics of the renal transplant recipients by education

Characteristics	Total (N)	Education Attainment, n (%)			P-Value
		No/Primary	Secondary	Tertiary	
Age, mean ± SD	409	57.6 ± 13.8	47.4 ± 13.1	43.6 ± 13.5	**<0.001**
Gender					0.204
Male	229	28 (45.9)	92 (56.4)	109 (58.9)	
Female	180	33 (54.1)	71 (43.6)	76 (41.1)	
Ethnicity					**<0.001**
Malay	130	5 (8.2)	47 (28.8)	78 (42.2)	
Chinese	228	54 (88.5)	97 (59.5)	77 (41.6)	
Indian	42	2 (3.3)	17 (10.4)	23 (12.4)	
Others	9	0 (0)	2 (1.2)	7 (3.8)	
Employment Status					**<0.001**
Unemployed	44	8 (13)	22 (13)	14 (8)	
Outside Workforce	109	30 (49)	44 (27)	35 (19)	
Employed	256	23 (38)	97 (60)	136 (73)	
Employment Sector					**<0.001**
Public	44	1 (2)	8 (5)	35 (19)	
Private	143	16 (26)	51 (31)	76 (41)	
Self-employed	86	13 (21)	39 (24)	34 (18)	
Unemployed	136	31 (51)	65 (40)	40 (22)	
Marital Status					**0.007**
Single	117	8 (13.1)	45 (27.6)	64 (34.6)	
Married	270	46 (75.4)	110 (67.5)	114 (61.2)	
Others	22	7 (11.5)	8 (4.9)	7 (3.8)	
Household Income[1, #]					**<0.001**
Bottom 40%	152	28 (47.5)	82 (51.9)	42 (23.2)	
Middle 40%	145	19 (22.2)	56 (35.4)	70 (38.7)	
Top 20%	101	12 (20.3)	20 (12.7)	69 (38.1)	
Geographical Location					**0.021**
Greater Kuala Lumpur	295	44 (73.3)	106 (65.0)	145 (78.4)	
Others	113	16 (26.7)	57 (35.0)	40 (21.6)	

SD, standard deviation;

[1] Household income classified as Bottom 40%, <RM4360 (< USD 1042.04); Middle 40%, RM4360–RM9619 (USD 1042.04 – USD 2298.94); Top 20%, >RM9619 (> USD 2298.94)

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Table 4.18 shows the socio-demographic characteristics of renal transplant recipients by educational attainment. The mean age of RTRs are higher with lower educational attainment; 57.6 years for primary-level or no education, 47.4 years for secondary level and 43.6 years for tertiary-level. Male RTRs make up the majority in the secondary and tertiary-level educational attainment at 56.4% and 58.9% respectively except for primary-level or no education, whereby females (54.1%) make the majority. Most of the ethnicities (Malay, Indian and Others) have an incremental proportion as the educational attainment progresses. However, the trend is reversed for the Chinese. The primary-level was the highest at 88.5%, followed by secondary-level at 59.5% and lowest at tertiary-level at 41.6%.

It can be noted that most of the bottom 40% household income has no/primary (47.5%) and secondary (51.9%) educational attainment, while tertiary-level consist of mainly middle 40% (38.7%) and top 20% (38.1%). The no/primary and secondary-level educational attainment are mainly unemployed RTRs with 51% and 40% respectively. Single RTRs proportion increases with educational attainment from primary-level (13.1%) to secondary level (27.6%) and lastly tertiary-level (34.6%). However, for married and others (widows and divorcees), the trend is reversed. Greater Kuala Lumpur was the residence of a relatively equal proportion of RTRs from different educational attainment gradient, primary-level (73.3%), secondary-level (65.0%) and tertiary-level (78.4%).

Characteristics that showed statistically significant for educational attainment were age, ethnicity, employment status, employment sector, marital status, household income and geographical location.

b. Medical Characteristics Renal Transplantation Recipients by Educational Attainment from Survey

Table 4.19: Medical characteristics of renal transplant recipients by educational attainment

Characteristics	Total (N)	Education, n (%)			P-Value
		No/Primary	Secondary	Tertiary	
Pre-Transplantation					
Donor type					**<0.001**
Living	255	21 (34.4)	91 (55.8)	143 (77.7)	
Deceased	153	40 (65.6)	72 (44.2)	41 (22.3)	
Transplant Centre					**<0.001**
Local	248	23 (24.6)	97 (59.5)	128 (69.2)	
Overseas	160	38 (62.3)	65 (40.5)	57 (30.8)	
Perceived preparedness for transplant[1]					
Physical	379	55 (90.1)	150 (92.0)	174 (94.1)	0.553
Emotional	374	55 (90.1)	149 (91.4)	170 (91.9)	0.916
Spiritual	377	56 (91.8)	150 (92.0)	171 (92.4)	0.983
Financial	322	45 (73.7)	124 (76.1)	153 (82.7)	0.190
Duration of Dialysis (months), Median (IQR)	407	11.0 (3.0, 24.0)	12.0 (6.0, 36.0)	15.0 (5.0, 36.0)	0.077
Post-Transplantation					
Follow-up Compliance	347	47 (77.0)	137 (84.0)	163 (88.1)	0.106
Medication Compliance	399	59 (96.7)	157 (96.3)	183 (97.3)	0.264
Duration Since Transplant (months), Median (IQR)	407	168.0 (106.0, 245.0)	115.0 (60.0, 168.0)	92.0 (35.5, 144.0)	**<0.001**
Comorbidities[1]					
Diabetes	99	15 (24.6)	39 (23.9)	45 (24.3)	0.993
Hypertension	260	39 (63.9)	112 (68.7)	109 (58.9)	0.166
Coronary Heart Disease	37	6 (9.8)	12 (7.4)	19 (10.2)	0.623
Cerebrovascular Disease	9	1 (1.6)	3 (1.8)	5 (2.7)	0.817
Cancer	5	0 (0)	3 (1.8)	2 (1.1)	0.522
Multimorbidity (≥2)	94	14 (23.0)	38 (23.3)	42 (22.7)	0.911
Healthcare Provider					0.468
Ministry of Health	287	39 (63.9)	118 (72.4)	130 (70.2)	
Ministry of Education	122	22 (36.1)	45 (21.6)	55 (29.8)	

IQR, interquartile range

[1] The comorbidities and perceived preparedness are questions with multiple choice for RTRs to select yes or no

Table 4.19 shows the medical characteristics of renal transplant recipients by educational attainment that could be categorized into Pre-Transplantation and Post-Transplantation characteristics. The higher the educational attainment, the more likely the RTRs received living renal transplantation with primary-level or no education at 34.4%, secondary-level at 55.8% and tertiary-level at 77.7%.

Similarly, the higher the educational attainment, the more likely RTRs select a local transplant centre at 24.6%, 59.5% and 69.2% for primary-level, secondary-level and tertiary-level respectively. The median duration of dialysis showed an incremental increase with educational level with no/ primary-level educational attainment is at 11.0 months, for secondary-level educational attainment at 12.0 months and tertiary-level educational attainment at 15.0 months. Pre-transplantation characteristics that showed statistical significance for educational attainment were donor type and transplant centre.

For Post-Transplantation outpatient medical follow-up compliance, the RTRs adherence improves from primary-level (77%) to secondary-level (84.0%) and lastly to tertiary-level (88.1%). The medication compliance of the RTRs is relatively similar across the educational attainment gradient. Similarly, the proportion of chronic diseases like diabetes, hypertension, coronary heart disease, cerebrovascular disease and cancer post-transplantation is similar across the educational attainment gradient. The RTRs with primary-level (36.1%) and tertiary-level educational attainment (29.8%) has a higher number of proportions compared to secondary-level (21.6%) utilizing the Ministry of Education healthcare facilities. Duration since transplant was the only post-transplantation characteristic that was statistically significant for educational attainment.

4.4.4.2 Household Income

a. Socio-Demographic Characteristics Renal Transplantation Recipients by Household Income from Survey

Table 4.20: Socio-demographic characteristics of the renal transplant recipients by household income

Characteristics	Total (N)	Household Income, n (%)[1, #]			P-Value
		Bottom 40%	Middle 40%	Top 20%	
Age, mean ± SD	398	45.5 ± 15.6	48.0 ± 12.7	43.4 ± 13.60	0.195
Gender					**0.036**
Male	223	76 (50.0)	80 (55.0)	67 (66)	
Female	175	76 (50.0)	65 (45.0)	34 (34)	
Ethnicity					0.548
Malay	127	52 (34.2)	41 (28.3)	34 (33.7)	
Chinese	220	77 (50.7)	90 (62.1)	53 (52.5)	
Indian	42	19 (12.5)	11 (7.6)	12 (11.9)	
Others	9	4 (2.6)	3 (2.1)	2 (2.0)	
Employment Status					**0.008**
Unemployed	43	22 (14)	17 (12)	4 (4)	
Outside Workforce	104	48 (32)	35 (24)	21 (21)	
Employed	251	82 (54)	93 (64)	76 (75)	
Employment Sector					**0.001**
Public	43	8 (5.3)	16 (11.0)	19 (18.8)	
Private	141	49 (32.2)	54 (37.2)	38 (37.6)	
Self-employed	83	28 (18.4)	32 (22.1)	23 (22.8)	
Unemployed	131	67 (44.1)	43 (29.7)	21 (20.8)	
Marital Status					**0.001**
Single	113	56 (36.8)	38 (26.2)	19 (18.8)	
Married	263	83 (54.6)	100 (69.0)	80 (79.2)	
Others	22	13 (8.6)	7 (4.8)	2 (2.0)	
Educational Attainment					**<0.001**
No Education / Primary	59	28 (18.4)	19 (13.1)	12 (11.9)	
Secondary	158	82 (53.9)	56 (38.6)	20 (19.8)	
Tertiary	181	42 (27.6)	70 (48.3)	69 (68.3)	
Geographical Location					0.458
Greater Kuala Lumpur	112	110 (72.8)	99 (68.3)	76 (75.2)	
Others	285	41 (27.2)	46 (31.7)	25 (24.8)	

SD, standard deviation

[1] Household income classified as Bottom 40%, <RM4360 (< USD 1042.04); Middle 40%, RM4360–RM9619 (USD 1042.04 – USD 2298.94); Top 20%, >RM9619 (> USD 2298.94)

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Table 4.20 shows the socio-demographic characteristics of renal transplant recipients by household income. The mean age of RTRs is highest for the middle 40% household income (48 years), followed by the bottom 40% household income (45.5 years) and finally top 20% (43.4%). The Chinese have the highest proportion in the middle 40% subgroup while the Malays (34.2%), Indians (12.5%) and Others (2.6%) have the highest proportion in the bottom 40% household income subgroup.

The RTRs that are in the middle 40% subgroup (48.3%) and top 20% subgroup (68.3%) attained mostly tertiary-level educational attainment. For the household income subgroups, the majority of the RTRs resides in the greater Kuala Lumpur with bottom 40% at 72.8%, middle 40% at 86.3% and top 20% at 75.2%. Both RTRs in middle 40% household income subgroup (37.2%) and top 20% household income subgroup (37.6%) were mostly employed in the private sector. As anticipated, the employed RTRs proportion increases across the household income gradient of bottom 40% (54%), middle 40% (64%) and top 20% (75%) but is inverted for RTRs who are the unemployed and outside workforce. For singles and others (widows and divorcees) have an inverse relationship with the household income gradient.

Socio-demographic characteristics that showed statistical significance for household income were gender, employment status, employment sector, marital status and educational attainment.

b. Medical Characteristics Renal Transplantation Recipients by Household Income from Survey

Table 4.21: Medical characteristics of renal transplant recipients by household income

Characteristics	Total (N)	Household income, n (%)[1, #]			P-Value
		Bottom 40%	Middle 40%	Top 20%	
Pre-Transplantation					
Donor type					0.091
Living	251	91 (59.9)	87 (60.4)	73 (77.3)	
Deceased	146	61 (40.1)	57 (39.6)	28 (22.7)	
Transplant Centre					0.871
Local	242	93 (61.6)	87 (59.6)	63 (62.4)	
Overseas	155	58 (38.4)	59 (40.4)	38 (37.6)	
Perceived preparedness for transplant[2]					
Physical	398	135 (88.8)	135 (93.1)	98 (97.0)	0.050
Emotional	398	134 (88.2)	134 (92.4)	95 (94.1)	0.218
Spiritual	398	136 (89.4)	132 (90.4)	98 (97.0)	0.084
Financial	398	136 (89.4)	118 (81.4)	91 (90.0)	**<0.001**
Duration of Dialysis (months), Median (IQR)	407	11.0 (6.0, 36.0)	12.0 (3.5, 42.0)	15.0 (3.0, 36.0)	**0.016**
Post-Transplantation					
Follow-up Compliance	347	127 (83.5)	124 (85.6)	85 (84.2)	0.894
Medication Compliance	399	144 (94.7)	143 (98.6)	101 (100.0)	**0.018**
Duration Since Transplant (months), Median (IQR)	407	168.0 (48.0, 173.0)	115.0 (53.0, 172.0)	92.0 (46.5, 166.0)	0.720
Comorbidities[2]					
Diabetes Mellitus	99	31 (2.0)	37 (25.6)	28 (27.7)	0.364
Hypertension	260	94 (61.8)	93 (64.1)	66 (65.3)	0.838
Coronary Heart Disease	37	13 (8.6)	12 (8.3)	11 (10.8)	0.753
Cerebrovascular Disease	9	1 (0.7)	5 (3.4)	3 (3.0)	0.231
Cancer	5	5 (3.3)	0 (0.0)	0 (0.0)	**0.017**
Multimorbidity (≥2)	94	31 (2.0)	34 (23.4)	26 (25.7)	0.598
Healthcare Provider					0.469
Ministry of Health	287	39 (64)	118 (72)	130 (70)	
Ministry of Education	122	22 (36)	45 (28)	55 (30)	

IQR, interquartile range

[1] Household income classified as Bottom 40%, <RM4360 (< USD 1042.04); Middle 40%, RM4360–RM9619 (USD 1042.04 – USD 2298.94); Top 20%, >RM9619 (> USD 2298.94)

[2] The comorbidities and perceived preparedness are questions with multiple choices

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Meanwhile, Table 4.21 shows the medical characteristics of renal transplant recipients by household income. The proportion of deceased renal transplantation decreases across the household income gradient. The middle 40% income subgroup has a higher proportion of RTRs who received their renal transplant from overseas transplant centre at 40.4% compared to 38.4% and 37.6% for bottom 40% and top 20% respectively. Perceived financial preparedness for renal transplantation is shown to be lowest for the middle 40% household income subgroup at 81.44%. The median duration for dialysis is highest for the top 20% household income RTRs at 15 months (interquartile range 3.0-36.0). It was followed by the middle 40% household income RTRs at 12 months (interquartile range 3.5-42.0) and bottom 40% household income RTRs at 11 months (interquartile range 6.0-36.0). Pre-transplantation characteristics that showed statistical significance were perceived financial preparedness for transplant and the duration of dialysis.

The medication compliance of the RTRs is incremental based on the household income gradient at 94.7%, 98.6% and 100% for the bottom 40%, middle 40% and top 20% respectively. The compliance rate for the outpatient medical follow-up is relatively similar for all household income subgroups. The chronic diseases such as diabetes, hypertension, coronary heart disease and multimorbidity are seen to be most common at the top 20% household income subgroup. The number of cancer cases among RTRs was noted exclusively in the bottom 40% income subgroup with five RTRs. Post-transplantation characteristics that showed statistical significance were medication compliance and cancer as comorbid.

4.4.4.3 Employment Status

b. Socio-demographic Characteristics Renal Transplantation Recipients by Employment Status from Survey

Table 4.22: Socio-demographic characteristics of the renal transplant recipients by employment status

Characteristics	Total (N)	Employment status, n (%)			P-Value
		Unemployed	Outside Workforce	Employed	
Age, mean ± SD	409	47.0 ± 17.0	53.7 ± 16.5	44.6 ± 11.6	**<0.001**
Gender					**<0.001**
Male	229	22 (50.0)	45 (41.3)	162 (63.3)	
Female	180	22 (50.0)	64 (58.7)	94 (36.7)	
Ethnicity					0.453
Malay	130	12 (27.3)	29 (26.6)	89 (34.8)	
Chinese	228	28 (63.6)	68 (62.4)	132 (51.6)	
Indian	42	4 (9.1)	10 (9.2)	28 (10.9)	
Others	9	0 (0.0)	2 (1.8)	7 (2.7)	
Household Income[1, #]					**0.008**
Bottom 40%	152	22 (51.2)	48 (46.2)	82 (32.7)	
Middle 40%	145	17 (39.5)	35 (33.7)	93 (37.1)	
Top 20%	101	4 (9.3)	21 (20.2)	76 (30.3)	
Marital Status					**0.007**
Single	117	19 (43.2)	18 (16.5)	80 (31.3)	
Married	270	22 (50.0)	84 (77.1)	164 (64.2)	
Others	22	3 (6.8)	7 (6.4)	12 (4.7)	
Educational Attainment					**<0.001**
No Education / Primary	61	8 (18.3)	30 (27.5)	23 (9.0)	
Secondary	163	22 (50.0)	44 (40.4)	97 (37.9)	
Tertiary	185	14 (31.8)	35 (32.1)	136 (53.1)	
Employment Sector					**<0.001**
Public	44	0 (0.0)	10 (9.2)	34 (13.3)	
Private	143	0 (0.0)	12 (11.0)	131 (51.2)	
Self-employed	86	1 (2.3)	6 (5.5)	79 (30.9)	
Unemployed	136	43 (97.8)	81 (74.3)	12 (4.7)	
Geographical Location					0.602
Greater KL	295	29 (65.9)	80 (73.4)	186 (72.9)	
Others	113	15 (34.1)	29 (26.6)	69 (27.1)	

SD, standard deviation; KL, Kuala Lumpur

[1] Household income classified as Bottom 40%, <RM4360 (< USD 1042.04); Middle 40%, RM4360–RM9619 (USD 1042.04 – USD 2298.94); Top 20%, >RM9619 (> USD 2298.94)

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Table 4.22 indicates the socio-demographic characteristics of renal transplant recipients by employment status. The RTRs who are outside the workforce has the highest mean for age at 53.7 years. There is an equal number of unemployed males and females, while males are more employed (63.3%) and females are mostly outside the workforce (58.7%). The Chinese have an inverse relationship with employment status with the highest for unemployed RTRs (63.6%), followed by outside workforce (62.4%) and lastly employed RTRs (51.6%). The bottom 40% household income subgroup is represented by the RTRs in the unemployed and outside workforce subgroup with 51.2% and 46.2%, respectively. The employed RTRs have a fairly equal distribution amongst the household income subgroups, bottom 40% (32.7%), middle 40% (37.1%) and top 20% (30.3%).

RTRs with secondary-level and primary-level educational attainment showed an inverse relationship with the employment status gradient. At the same time, for tertiary-level, it follows the gradient with unemployed at 31.8%, outside workforce at 32.1% and employed at 53.1%. More RTRs are outside the workforce (73.4%) and employed (72.9%) living in the greater Kuala Lumpur compared to unemployed RTRs (65.9%).

The socio-demographic characteristics that showed statistical significance were age, gender, household income, marital status, employment sector and educational attainment.

c. Medical Characteristics Renal Transplantation Recipients by Employment Status from Survey

Table 4.23: Medical characteristics of renal transplant recipients by employment status

Characteristics	Total (N)	Employment status, n (%)			P-Value
		Unemployed	Outside Workforce	Employed	
Pre-Transplantation					
Donor Type					0.052
Living	255	27 (61.4)	58 (53.2)	170 (66.7)	
Deceased	153	17 (38.6)	51 (46.8)	85 (33.3)	
Transplant Centre					0.070
Local	248	24 (54.5)	58 (53.2)	166 (65.1)	
Overseas	160	20 (45.5)	51 (46.8)	89 (34.9)	
Perceived Preparedness for Transplant[1]					
Physical	379	40 (90.9)	104 (95.4)	235 (92.2)	0.429
Emotional	374	39 (88.6)	103 (93.6)	232 (91.0)	0.375
Spiritual	377	39 (88.6)	101 (92.7)	237 (92.9)	0.651
Financial	322	34 (77.3)	86 (78.9)	202 (79.2)	0.969
Duration of Dialysis (months), Median (IQR)	407	24.0 (3.8, 48.0)	12.0 (2.3, 35.0)	12.0 (6.0, 36.0)	0.236
Post-Transplantation					
Follow-up Compliance	347	39 (88.6)	94 (86.2)	214 (83.9)	0.616
Medication Compliance	399	43 (97.7)	107 (98.2)	249 (97.6)	0.876
Duration since Transplant (months), Median (IQR)	407	106.0 (37.8, 148.8)	135.0 (68.3, 189.0)	124.1 (45.0, 163.0)	**0.014**
Comorbidities[1]					
Diabetes Mellitus	99	12 (27.3)	29 (26.6)	58 (22.7)	0.637
Hypertension	260	28 (63.6)	71 (65.1)	161 (63.1)	0.920
Coronary Heart Disease	37	3 (6.8)	12 (11.0)	22 (8.6)	0.657
Cerebrovascular Disease	9	3 (6.8)	3 (2.8)	3 (1.1)	0.056
Cancer	5	3 (6.8)	1 (0.9)	1 (0.4)	0.002
Multimorbidity (≥2)	94	12 (27.3)	28 (2.6)	54 (21.2)	0.491
Healthcare Provider					0.381
Ministry of Health	287	34 (77.3)	79 (72.5)	174 (68.0)	
Ministry of Education	122	10 (22.7)	30 (27.5)	82 (32.0)	

IQR, interquartile range

[1] The perceived preparedness and comorbidities are questions with multiple choice for RTRs to select yes or no

Table 4.23 shows the medical characteristics of renal transplant recipients by employment status. RTRs who are outside the workforce (46.8%) seem to be more likely to undergo deceased kidney donation compared to the unemployed (38.6%) and employed (33.3%) RTRs. Employed RTRs (65.1%) are more likely to undergo renal transplantation locally compared to RTRs who are unemployed (54.5%) and outside workforce (53.2%). The median duration of dialysis for employment status shows a reverse in trend with the unemployed RTRs having the most prolonged duration for dialysis at 24.0 months (interquartile range 3.8- 48.0). It is followed by RTRs who are outside the workforce and employed with 12.0 months (interquartile range 2.3-35.0). Similarly, to household income, the perceived financial preparedness of RTRs follows the socioeconomic gradient for employment status.

Hypertension is the most common chronic disease among RTRs at 63.6% for unemployed RTRs, 65.1% for RTRs outside the workforce and 63.1% for employed RTRs. The compliance of RTRs to their medical follow-up is highest for the unemployed (88.6%), followed by outside workforce (86.2%) and employed (83.9%). RTRs who are outside workforce has the longest median for post-transplantation duration at 135 months. The utilization of the Ministry of Education's facilities is incremental with the employment status gradient at 22.7%, 27.5% and 32.0% for the unemployed, outside workforce and employed subgroups. Duration of since transplant was the only medical characteristic that was statistically significant for employment status.

4.4.5 Association between Levels of Socioeconomic Status and Post-Transplantation Quality of Life

4.4.5.1 Educational Attainment

Table 4.24: Distribution of WHOQOL domain scores by levels of educational attainment

Domain	Education Attainment	Mean ± SD	P-Value
Physical			**0.010**
	None / Primary	65.8 ± 15.0	
	Secondary	68.9 ± 15.9	
	Tertiary	71.9 ± 14.7	
Psychological			**<0.001**
	None / Primary	66.8 ± 13.9	
	Secondary	70.8 ± 15.3	
	Tertiary	74.4 ±13.3	
Social			**0.002**
	None / Primary	63.6 ± 17.0	
	Secondary	68.9 ± 17.4	
	Tertiary	72.3 ± 15.7	
Environment			**<0.001**
	None / Primary	62.6 ± 13.7	
	Secondary	66.7 ± 14.1	
	Tertiary	71.1 ±12.9	
Overall QOL			**<0.001**
	None / Primary	65.0 ± 12.8	
	Secondary	69.0 ± 13.8	
	Tertiary	72.4 ± 12.4	

SD, standard deviation; QOL, Quality of Life

Table 4.24 shows the mean value for the different WHOQOL domains and the association between educational attainment and WHOQOL domains. The association between educational attainment and all the WHOQOL domains were statistically significant (P-Value <0.05). The scores showed a socioeconomic gradient with tertiary-level educational attainment having the highest mean for all the WHOQOL domains, followed by mean score of secondary-level and lastly primary-level or no educational attainment have the lowest mean in all the domains.

Table 4.25: Crude and adjusted differences between educational attainment and WHOQOL domains

Domain	Characteristics	Crude Difference (95% CI)	P-Value	Adjusted Difference (95% CI)[1]	P-Value
Physical					
	None / Primary	-6.1 (-10.5, -1.7)	**0.007**	-5.5 (-10.3, -0.6)	**0.027**
	Secondary	-2.1 (-6.2, 0.2)	0.068	-2.9 (-6.2, 0.7)	0.081
	Tertiary	0 (reference)		0 (reference)	
	Trend for P-Value		**0.004**		**0.016**
Psychological					
	None / Primary	-7.6 (-11.7, -3.5)	**<0.001**	-6.6 (-11.3, -2.1)	**0.004**
	Secondary	-3.6 (-6.6, -0.6)	**0.028**	-3.4 (-6.5, -0.5)	**0.024**
	Tertiary	0 (reference)		0 (reference)	
	Trend for P-Value		**<0.001**		**0.002**
Social					
	None / Primary	-8.7 (13.6, -3.9)	**<0.001**	-8.1 (-13.5, -2.8)	**0.003**
	Secondary	-3.4 (-7.0, 0.2)	0.062	-3.7 (-7.3, -0.1)	**0.047**
	Tertiary	0 (reference)		0 (reference)	
	Trend for P-Value		**<0.001**		**0.002**
Environment					
	None / Primary	-8.5 (-12.3, -4.6)	**<0.001**	-7.9 (-12.1, -3.7)	**<0.001**
	Secondary	-4.33 (-7.2, -1.5)	**0.003**	-4.4 (-7.3, - 1.5)	**0.003**
	Tertiary	0 (reference)		0 (reference)	
	Trend for P-Value		**<0.001**		**<0.001**
Overall QOL					
	None / Primary	-7.4 (-11.2, -3.6)	**<0.001**	-6.7 (-10.9, -2.5)	**0.002**
	Secondary	-3.4 (-6.18, -0.6)	**0.018**	-3.4 (-6.2, -0.5)	**0.020**
	Tertiary	0 (reference)		0 (reference)	
	Trend for P-Value		**<0.001**		**0.001**

CI, confidence interval; QOL, Quality of Life

[1] Adjusted for age, ethnicity, gender, geographical location and household income

Table 4.25 presents the crude and adjusted difference between different levels of educational attainment and WHOQOL domains. Lower levels of educational attainment are significantly associated with lower scores of WHOQOL Physical domain (adjusted $P_{Trend} = 0.016$). RTRs with none or primary educational attainment (adjusted difference -5.5, 95%CI: [-10.3, -0.6]) and secondary educational attainment (adjusted difference -2.9, 95%CI: [-6.2, 0.7]) have lower scores compared to RTRs with tertiary education.

Lower levels of educational attainment are significantly associated with lower scores of WHOQOL Psychological domain (adjusted $P_{Trend} = 0.002$). RTRs with none or primary educational attainment (adjusted difference -6.6, 95%CI: [-11.3, -2.1]) and secondary educational attainment (adjusted difference -3.4, 95%CI: [-6.5, 0.5]) have lower scores compared to RTRs with tertiary education.

Lower levels of educational attainment are significantly associated with lower scores of WHOQOL Social domain (adjusted $P_{Trend} = 0.002$). RTRs with none or primary educational attainment (adjusted difference -8.1, 95%CI: [-13.5, -2.8]) and secondary educational attainment (adjusted difference -3.7, 95%CI: [-7.3, -0.1]) have lower scores compared to RTRs with tertiary education.

Lower levels of educational attainment are significantly associated with lower scores of WHOQOL Environment domain (adjusted $P_{Trend} < 0.001$). RTRs with none or primary educational attainment (adjusted difference -7.9, 95%CI: [-12.1, -3.7]) and secondary educational attainment (adjusted difference -3.4, 95%CI: [-7.3, -1.5]) have lower scores compared to RTRs with tertiary education.

Lower levels of educational attainment is significantly associated with lower scores of WHOQOL Overall QOL (adjusted $P_{Trend} = 0.001$). RTRs with none or primary educational attainment (adjusted difference -6.7, 95%CI: [-10.9, -2.8]) and secondary educational attainment (adjusted difference -3.4, 95%CI: [-6.2, -0.5]) have lower scores compared to RTRs with tertiary education.

4.4.5.2 Household Income

Table 4.26: Distribution of WHOQOL domain scores by levels of household income

Domain	Household income [1, #]	Mean ± SD	P-Value
Physical			**0.001**
	Bottom 40%	66.5 ± 13.8	
	Middle 40%	71.9 ± 16.6	
	Top 20%	75.4 ± 14.7	
Psychological			**0.001**
	Bottom 40%	68.4 ± 14.4	
	Middle 40%	73.7 ± 14.2	
	Top 20%	75.4 ±13.5	
Social			**0.003**
	Bottom 40%	66.0 ± 18.0	
	Middle 40%	72.9 ± 15.4	
	Top 20%	70.9 ± 15.8	
Environment			**<0.001**
	Bottom 40%	64.6 ± 13.7	
	Middle 40%	69.6 ± 13.3	
	Top 20%	72.0 ± 13.8	
Overall QOL			**<0.001**
	Bottom 40%	66.2 ± 13.1	
	Middle 40%	72.2 ± 13.1	
	Top 20%	72.9 ± 12.6	

SD, standard deviation; QOL, Quality of Life

[1] Household income classified as Bottom 40%, <RM4360 (< USD 1042.04); Middle 40%, RM4360–RM9619 (USD 1042.04 – USD 2298.94); Top 20%, >RM9619 (> USD 2298.94)

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

The mean value for the different domains of WHOQOL and the association between household income and WHOQOL domains are showed in table 4.26. The results show that all of the WHOQOL domains have a significant association with household income. The top 20% household income subgroup has the highest mean for all the WHOQOL domains, followed by the Middle 40% household income subgroup and the Bottom 40% household income subgroup has the lowest mean. All the domains demonstrate a statistical significance for household income.

Table 4.27: Crude and adjusted differences between household income and WHOQOL domains

Domain	Characteristics [2, #]	Crude Difference (95% CI)	P-Value	Adjusted Difference (95% CI)[1]	P-Value
Physical					
	Bottom 40%	-5.9 (-9.7, -2.1)	**0.002**	-4.6 (-8.4, -0.8)	**0.017**
	Middle 40%	-0.4 (-4.3, 3.4)	0.823	0.5 (-3.2, 4.3)	0.779
	Top 20%	0 (reference)		0 (reference)	
	Trend for P-Value		**0.001**		**0.009**
Psychological					
	Bottom 40%	-7.0 (-10.5, -3.4)	**<0.001**	-6.7 (-10.2, -3.9)	**<0.001**
	Middle 40%	-1.7 (-5.3, 1.9)	0.344	-1.1 (-4.6, 2.4)	0.540
	Top 20%	0 (reference)		0 (reference)	
	Trend for P-Value		**<0.001**		**<0.001**
Social					
	Bottom 40%	-4.9 (-9.1, -0.7)	**0.023**	-4.1 (-8.3, 0.2)	0.058
	Middle 40%	2.0 (-2.29, 6.3)	0.363	2.3 (-1.91, 6.5)	0.285
	Top 20%	0 (reference)		0 (reference)	
	Trend for P-Value		**0.010**		**0.031**
Environment					
	Bottom 40%	-7.6 (-11.0, -4.2)	**<0.001**	-7.7 (-11.1, -4.3)	**<0.001**
	Middle 40%	-2.4 (-5.8, 1.2	0.178	-2.0 (-5.3, 1.4)	0.252
	Top 20%	0 (reference)		0 (reference)	
	Trend for P-Value		**<0.001**		**<0.001**
Overall QOL					
	Bottom 40%	-6.6 (-9.9, -3.3)	**<0.001**	-6.0 (-9.3, -2.8)	**<0.001**
	Middle 40%	-0.6 (-3.9, 2.8)	0.740	-0.2 (-3.4, 3.2)	0.923
	Top 20%	0 (reference)		0 (reference)	
	Trend for P-Value		**<0.001**		**<0.001**

[1] Adjusted for age, ethnicity, gender, geographical location, employment status and employment sector

[2] Household income classified as Bottom 40%, <RM4360 (< USD 1042.04); Middle 40%, RM4360–RM9619 (USD 1042.04 – USD 2298.94); Top 20%, >RM9619 (> USD 2298.94)

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Table 4.27 presents the crude and adjusted difference between different levels of educational attainment and WHOQOL domains. Lower levels of household income are significantly associated with lower scores of WHOQOL Physical domain (adjusted P_{Trend} = 0.009). RTRs with Bottom 40% household income (adjusted difference -4.6, 95%CI: [-8.4, -0.8]) and Middle 40% household income (adjusted difference 0.5, 95%CI: [-3.2, 4.3]) have lower scores compared to RTRs with Top 20% household income.

Lower levels of household income are significantly associated with lower scores of WHOQOL Psychological domain (adjusted P_{Trend} < 0.001). RTRs with Bottom 40% household income (adjusted difference -6.7, 95%CI: [-10.2, -3.9]) and Middle 40% household income (adjusted difference -1.1, 95%CI: [-4.6, 2.4]) have lower scores compared to RTRs with Top 20% household income.

Lower levels of educational attainment are significantly associated with lower scores of WHOQOL Social domain (adjusted P_{Trend} = 0.031). Only RTRs with Bottom 40% household income (adjusted difference -4.1, 95%CI: [-8.3, 0.2]) have lower scores compared to RTRs with Top 20% household income.

Lower levels of household income are significantly associated with lower scores of WHOQOL Environment domain (adjusted P_{Trend} < 0.001). RTRs with Bottom 40% household income (adjusted difference -7.7, 95%CI: [-11.1, -4.3]) and Middle 40% household income (adjusted difference -2.0, 95%CI: [-5.3, 1.4]) have lower scores compared to RTRs with Top 20% household income.

Lower levels of household income are significantly associated with lower scores of WHOQOL Overall QOL (adjusted P_{Trend} < 0.001). RTRs with Bottom 40% household income (adjusted difference -6.0, 95%CI: [-9.3, -2.8]) and Middle 40% household income (adjusted difference -0.2, 95%CI: [-3.4, 3.2]) have lower scores compared to RTRs with Top 20% household income.

4.4.5.3 Employment Status

Table 4.28: Distribution of WHOQOL domain scores by levels of employment status

Domain	Employment Status	Mean ± SD	P-Value
Physical			**0.004**
	Unemployed	62.7 ± 16.7	
	Outside Workforce	69.0 ± 16.1	
	Employed	71.4 ± 14.5	
Psychological			0.218
	Unemployed	67.5 ± 15.4	
	Outside Workforce	73.0 ± 14.6	
	Employed	72.1 ± 14.1	
Social			**0.034**
	Unemployed	63.5 ± 18.0	
	Outside Workforce	68.6 ± 17.2	
	Employed	71.1 ± 16.3	
Environment			0.208
	Unemployed	64.6 ± 13.8	
	Outside Workforce	69.8 ± 14.6	
	Employed	67.9 ± 13.4	
Overall QOL			0.057
	Unemployed	65.1 ± 13.4	
	Outside Workforce	70.0 ± 13.8	
	Employed	70.7 ± 12.9	

SD, standard deviation; QOL, Quality of Life
Outside workforce; retirees, homemakers, students

Table 4.28 shows the mean values for domains of WHOQOL and the association of the employment status of unemployed, outside workforce and employed between the WHOQOL domains. The statistically significant WHOQOL domains towards Employment Status are the Physical Health domain and Social domain only. There is a socioeconomic gradient for the mean score for WHOQOL domains with unemployed RTRs scoring the lowest in all the WHOQOL domains.

Table 4.29: Crude and adjusted differences between employment status and WHOQOL domains

Domain	Characteristics	Crude Difference (95% CI)	P-Value	Adjusted Difference (95% CI)[1]	P-Value
Physical					
	Unemployed	-8.6 (-13.5, -3.8)	**<0.001**	-7.7 (-12.6, -2.9)	**0.002**
	Outside Workforce	-2.4 (-5.8, 1.0)	0.167	-1.6 (-5.2, 2.0)	0.395
	Employed	0 (reference)		0 (reference)	
	Trend for P-Value		**0.001**		**0.004**
Psychological					
	Unemployed	-4.5 (-9.1, 0.1)	0.052	-3.2 (-7.7, 1.3)	0.159
	Outside Workforce	0.9 (-2.3, 4.1)	0.574	2.1 (-1.3, 5.4)	0.224
	Employed	0 (reference)		0 (reference)	
	Trend for P-Value		0.205		0.524
Social					
	Unemployed	-7.5 (-13.1, -2.0)	**0.008**	-6.8 (-12.3, -1.4)	**0.014**
	Outside Workforce	-2.4 (-6.2, 1.4)	0.210	-1.5 (-5.5, 2.6)	0.481
	Employed	0 (reference)		0 (reference)	
	Trend for P-Value		**0.008**		**0.022**
Environment					
	Unemployed	-3.4 (-7.8, 1.0)	0.132	-1.8 (-6.0, 2.5)	0.414
	Outside Workforce	1.9 (-1.2, 4.9)	0.238	3.6 (0.4, 6.8)	**0.027**
	Employed	0 (reference)		0 (reference)	
	Trend for P-Value		0.525		0.802
Overall QOL					
	Unemployed	-5.5 (-9.9, -1.1)	**0.014**	-4.6 (-8.8, -0.3)	**0.037**
	Outside Workforce	-0.6 (-3.6, 2.4)	0.696	0.6 (-2.6, 3.7)	0.733
	Employed	0 (reference)		0 (reference)	
	Trend for P-Value		**0.035**		0.123

CI, confidence interval; QOL, Quality of Life

Outside workforce; retirees, homemakers, students

[1] Adjusted for age, gender, ethnicity, geographical location and educational attainment

Table 4.29 presents the crude and adjusted difference between different levels of employment status and WHOQOL domains. Lower levels of employment status are significantly associated with lower scores of WHOQOL Physical domain (adjusted P_{Trend} = 0.004). RTRs who are unemployed (adjusted difference -7.7, 95%CI: [-12.6, -2.9]) and outside workforce (adjusted difference -1.6, 95%CI: [-5.2, 2.0]) have lower scores compared to RTRs who are employed.

Lower levels of employment status are significantly associated with lower scores of WHOQOL Social domain (adjusted P_{Trend} = 0.022). RTRs who are unemployed (adjusted difference -6.8, 95%CI: [-12.3, -1.4]) and outside workforce (adjusted difference -1.5, 95%CI: [-5.5, 2.6]) have lower scores compared to RTRs who are employed.

The association between employment status and WHOQOL Psychological and Environment domain as well as the Overall QOL did not achieve statistical significance.

4.4.6 Association between Levels of Socioeconomic Status and Prevalence of Post-Transplantation Financial Burden

4.4.6.1 Socio-Demographic Characteristics of Renal Transplant Recipients and Prevalence of Catastrophic Health Expenditure

Table 4.30: Socio-demographic characteristics of the renal transplant recipients by catastrophic health expenditure

Characteristics	Total (N)	Catastrophic Health Expenditure, n (%)		P-Value
		Yes	No	
Age, mean ± SD	397	49.6 ± 12.3	46.4 ± 14.6	**0.015**
Gender				0.060
Male	222	60 (64.5)	162 (53.5)	
Female	174	33 (35.5)	141 (46.5)	
Ethnicity				**<0.001**
Malay	127	10 (10.8)	117 (38.6)	
Chinese	219	78 (83.9)	141 (46.5)	
Indian	41	5 (5.4)	36 (11.9)	
Others	9	0 (0)	9 (3.0)	
Employment Status				0.942
Unemployed	43	11 (11.8)	32 (10.6)	
Outside Workforce	104	24 (25.8)	80 (26.4)	
Employed	249	58 (62.4)	191 (63.0)	
Employment Sector				0.185
Public	43	5 (5.4)	38 (12.5)	
Private	139	34 (36.6)	105 (34.7)	
Self-employed	83	24 (25.8)	59 (19.5)	
Unemployed	131	30 (32.3)	101 (33.3)	
Marital Status				**0.050**
Single	113	20 (21.5)	93 (30.7)	
Married	261	64 (68.8)	197 (65.0)	
Others	22	9 (9.7)	13 (4.3)	
Educational Attainment				0.353
No Education / Primary	58	17 (18.3)	41 (13.5)	
Secondary	158	39 (41.9)	119 (39.3)	
Tertiary	180	37 (39.8)	143 (47.2)	
Geographical Location				**0.038**
Greater KL	284	59 (63.4)	225 (74.5)	
Others	112	34 (36.6)	77 (25.5)	

SD, standard deviation; KL, Kuala Lumpur

The socio-demographic characteristics of RTRs stratified by catastrophic health expenditure (CHE) are shown in Table 4.30. The RTRs who experienced CHE have a mean age of 49.3 years compared to those non-CHE at 46.7 years. More males experience CHE (64.0%) compared to non-CHE (53.7%). Under ethnicity, Chinese make the majority of RTRs who experienced CHE (85.4%) compared to Malay (9.0%) and Indians (5.6%). RTRs who are employed were more likely to experience CHE at 64.0% followed by outside workforce (25.8%) and unemployed RTRs (10.1%). Very few RTRs who are employed at the public sectors experienced CHE with 4.5% compared to the others like the private sector (37.1%), self-employed (27.0%) and unemployed (31.5%).

More RTRs are retirees and divorcees (others) who experienced CHE (10.1%) compared to those who do not experience CHE (4.2%). For educational attainment, the RTRs who suffers from CHE in primary-level or no education is at 18%, in secondary-level is at 43.8% and tertiary-level is at 38.2%. The RTRs who resides in Greater Kuala Lumpur experiences CHE at 62.9% compared to 74.6% of RTRs who do not experience CHE. The variables that showed statistical significance (<0.05) are ethnicity, marital status and geographical location.

4.4.6.2 Medical Characteristics of Renal Transplant Recipients and Prevalence of Catastrophic Health Expenditure

Table 4.31: Medical characteristics of the renal transplant recipients by catastrophic health expenditure

Characteristics	Total (N)	Catastrophic Health Expenditure, n (%)		P-Value
		Yes	No	
Pre-Transplantation				
Donor type				0.599
Living	250	61 (65.6)	189 (62.6)	
Deceased	145	32 (34.4)	113 (37.4)	
Transplant Centre				**0.002**
Local	242	44 (47.3)	198 (65.6)	
Overseas	153	49 (52.7)	104 (34.4)	
Duration of dialysis (months), Median (IQR)	395	10.5 (2.0, 24.0)	17.0 (6.0, 38.0)	**<0.001**
Post-Transplantation				
Duration since transplant (months), Median (IQR)	395	99.0 (48.0, 178.5)	111.0 (54.75, 146.8)	**0.034**
Comorbidities[1]				
Diabetes Mellitus	96	25 (26.9)	71 (23.4)	0.497
Hypertension	251	62 (67.7)	189 (62.4)	0.452
Coronary Heart Disease	36	12 (12.9)	24 (7.9)	0.144
Cerebrovascular Disease	8	1 (1)	7 (2.3)	0.459
Cancer	5	1 (1)	4 (1.3)	0.853
Multimorbidity (≥2)	91	26 (28.0)	65 (21.5)	0.192
Healthcare Provider				**<0.001**
Ministry of Health	277	34 (26.6)	243 (80.2)	
Ministry of Education	119	59 (63.4)	60 (19.8)	

IQR, Interquartile range

[1] The comorbidities item is a question with multiple choice for RTRs to select

Table 4.31 shows the result of the medical characteristics of RTRs by CHE, which is divided into pre-transplantation and post-transplantation. From the table, the majority of the RTRs who are experiencing CHE are RTRs who has received living renal transplantation (65.2%). Renal transplantation overseas was a determinant factor in RTRs who experience CHE (52.8%) when compared to RTRs who do not suffer from CHE (35.0%). The median duration of RTRs who experiences CHE is at ten months (interquartile range 2.0, 24.0) which is much shorter than the non-CHE at 17.0 months (interquartile range 6.0, 38.0).

For a post-transplantation chronic disease like hypertension, diabetes, cancer and multimorbidity showed a similar proportion of RTRs who experience CHE and those without non-CHE were currently under the out-patient follow-up with the hospitals under the Ministry of Education (63.4%). The median duration of post-transplantation for RTRs who experience CHE (102.5 months) is shorter than RTRs who do not experience CHE (111.0 months). RTRs under the care of the Ministry of Education suffers from CHE (64.0%) more compared to RTRs who do not suffer from CHE (20.6%). Transplant centre, duration of dialysis and healthcare providers are the variables that were with statistically significant (<0.05).

4.4.6.3 Financial Characteristics of Renal Transplant Recipients and Prevalence of Catastrophic Health Expenditure

Table 4.32: Financial characteristics of the renal transplant recipients by catastrophic health expenditure

Characteristics	Total (N)	Catastrophic Health Expenditure, n (%)		P-Value
		Yes	No	
Household Income[1, #]				**0.005**
Bottom 40%	150	38 (40.9)	112 (37.2)	
Middle 40%	145	43 (46.2)	102 (33.9)	
Top 20%	99	12 (12.9)	87 (28.9)	
Out-of-pocket Payment[2]				
Current income	242	59 (63.4)	183 (60.4)	0.598
Savings	139	38 (40.9)	101 (33.3)	0.183
Bank Loan	9	1 (1.1)	8 (2.6)	0.376
Family/Friend Loan	32	13 (14.0)	19 (6.3)	**0.017**
Selling Assets	18	7 (7.5)	11 (3.6)	0.115
Reduce Household Spending	78	30 (32.3)	48 (15.8)	**<0.001**
Public Financing[2]				
Free healthcare	68	6 (6.5)	62 (20.4)	**0.002**
Community Welfare Department	14	2 (2.2)	12 (3.9)	0.408
Zakat[+]	2	0 (0)	2 (0.7)	0.432
Baitulmal[^]	5	0 (0)	5 (1.7)	0.213
Private Financing[2]				
Employee Insurance	25	2 (2.2)	22 (7.3)	0.071
Private Healthcare Insurance	26	9 (9.7)	17 (5.6)	0.166
Employee Provident Fund (EPF)	22	9 (9.7)	13 (4.3)	**0.047**
Social Security Organization (SOCSO)	7	5 (5.4)	2 (0.7)	**0.003**
Non-Governmental Organizations (NGO)	7	3 (3.2)	3 (1.0)	0.123
Perceived financial burden to health expenditure				**<0.001**
A Little	213	22 (24.7)	185 (61.3)	
Moderate	142	42 (31.5)	95 (31.5)	
Extreme	52	22 (7.3)	22 (7.3)	

[1] Household income classified as Bottom 40%, <RM4360 (< USD 1042.04); Middle 40%, RM4360–RM9619 (USD 1042.04 – USD 2298.94); Top 20%, >RM9619 (> USD 2298.94)

[2] Out of pocket payment, public financing and private financing are questions with multiple choice for RTRs to select

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

[+] Islamic social welfare system

[^] Public institution and trustee group that handles Islamic finance

Financial characteristics stratified by catastrophic health expenditure are tabulated in table 4.32. There are more RTRs in the bottom 40% who suffer from CHE (43.8%) than RTRs who are not suffering from CHE (35.7%) and similarly for the middle 40% experiencing CHE (44.9%) compared to non-CHE (33.8%). 245 of the RTRs are using out-of-pocket (OOP) payment to finance their post-transplantation care, with 64% of them suffering CHE. Other major OOP payments are using their saving (41.6%), reducing their household spending (33.7%) and receiving a loan from family or friends (15.7%). A total of 68 RTRs obtained subsidized healthcare from the government, and 14 RTRs received support from welfare. However, three and two RTRs respectively, are suffering from CHE.

For private financing, the RTRs who experience CHE most are the ones using their personal private healthcare insurance (11.2%) or employee provident fund (9.0%) for their post-transplantation care. Majority of the RTRs who are experiencing CHE has a moderate perceived financial burden from the medical expenditure due to post-transplantation care at 43.8%. Statistically significant variables ($p<0.05$) were household income, family/friend loan, reducing household spending, free public healthcare, Employee Provident Fund (EPF) and Social Security Organization (SOCSO) as well as the perceived financial burden by participants.

4.4.6.4 Association between Levels of Socioeconomic Status and Prevalent Odds of Catastrophic Health Expenditure

Table 4.33: Association between levels of socioeconomic status and prevalent odds of catastrophic health expenditure

Characteristics	Crude Odds Ratio (95% CI)	P-Value	Adjusted Odds Ratio (95% CI)[1]	P-Value
Education Attainment[a]				
No / Primary	1.6 (0.8, 3.2)	0.195	0.9 (0.4, 1.9)	0.719
Secondary	1.3 (0.8, 2.2)	0.331	0.9 (0.5, 1,7)	0.763
Tertiary	1 (reference)		1 (reference)	
Trend for P-Value		0.789		0.698
Household Income[b, 2, #]				
Bottom 40%	3.5 (1.5, 7.8)	**0.003**	5.3 (2.2, 12.7)	**<0.001**
Middle 40%	4.2 (1.9, 9.4)	**0.001**	4.7 (2.0, 11.0)	**<0.001**
Top 20%	1 (reference)		1 (reference)	
Trend for P-Value		**0.010**		**<0.001**
Employment Status[c]				
Unemployed	0.7 (0.3, 1.7)	0.429	0.6 (0.2, 1.4)	0.225
Outside Workforce	0.9 (0.5, 1.6)	0.675	0.9 (0.5, 1.7)	0.704
Employed	1 (reference)		1 (reference)	
Trend for P-Value		0.408		0.243

CI, confidence interval

[1a] Adjusted for age, gender, ethnicity and geographical location

[1b] Adjusted for age, gender, ethnicity, geographical location, employment status and employment sector

[1c] Adjusted for age, gender, ethnicity, geographical location and educational attainment

[2] Household income classified as Bottom 40%, <RM4360 (< USD 1042.04); Middle 40%, RM4360–RM9619 (USD 1042.04 – USD 2298.94); Top 20%, >RM9619 (> USD 2298.94)

[#] Conversion rate, RM 1 – USD 0.239 (Bank Negara Malaysia, 2019)

Table 4.33 summarized the crude and adjusted association between levels of socioeconomic status and the prevalent odds of CHE in RTRs. Lower household income was associated with higher prevalent odds for CHE (P_{Trend} =<0.001). Compared to RTRs with Top 20% household income, RTRs with Middle 40% household income and Bottom 40% household income had 4.7 times (adjusted odds ratio 4.7 95%CI: [2.2, 12.7]) and 5.3 times (adjusted odd ratio 5.3 95%CI: [0.5, 11.0]) higher prevalent odds for CHE, respectively. The association between the prevalent odds for CHE and educational attainment and employment status did not achieve statistical significance.

CHAPTER 5: DISCUSSION

5.1 Introduction

ReTRAPP study was designed to address the following objectives,

1. To describe key-informants' perception of the barriers and solutions to access renal transplantation in Malaysia
2. To examine the impact of socioeconomic status on access to renal transplant (waiting time to transplantation)
3. To determine the association of socioeconomic status on the survival of the renal transplant recipient (survival time)
4. To evaluate the influence of socioeconomic status on quality of life among renal transplant recipients
5. To compare the financial burden (catastrophic health expenditure) of renal transplant recipients according to their socioeconomic status

The findings from ReTRAPP are broad. Hence, it must be understood and adapted appropriately. The qualitative findings provide a holistic understanding of the issues in renal transplantation. Alternatively, the quantitative findings from the retrospective cohort study give a broad understanding of the access to renal transplantation and post-transplantation survival. However, the findings from the multi-centre cross-sectional study of QOL and financial burden are only a snapshot of the renal transplant recipients' continuum. In this chapter, key findings and discussion for each component of ReTRAPP are presented according to the research questions. The strengths and limitations of the ReTRAPP study are discussed in detail based on the methodological approaches adopted for this study.

5.2 Perceived Barriers and Solutions to Access Renal Transplantation in Malaysia

This research has thematically synthesized evidence of key barriers and solutions perceived by key-informants. It is guided by the socio-ecological model to identify a range of independent and interacting factors that influence renal transplantation in Malaysia. To our knowledge, this research is the first to explore the barriers and solutions to renal transplantation comprehensively in Malaysia as a whole.

Understanding the factors associated with health behaviours has been one of the significant challenges for researchers interested in the advance in the treatment of chronic diseases (Lee et al., 2011; Narayan et al., 2010; Schmidt et al., 2011). As a result, this research raised questions which must be discussed and included in the context of renal transplantation: the perception of the patients regarding renal transplantation and the "opting-out" system, and the implication of this to the transplantation service. These findings, in a Malaysian population, match the results of Morgan et al. (Morgan et al., 2003), leading to the conclusion of the existence of questions which are intrinsic to renal transplantation, the knowledge, attitude, and values of the patients in accepting renal transplantation will impact the routine of the doctors and their role to promote renal transplantation. The key-informants strongly believed that doctors who communicated consistently and more often had patients who were more willing to accept the doctor's choice of renal transplantation instead of dialysis (R. Morton et al., 2010). It was validated by Tumin et al. study that demonstrated the role of doctors in advocating for organ donation is highly valued by the public (Tumin, Ariffin, et al., 2014). Therefore, more proactive communication is necessary, especially when renal replacement therapy with an emphasis on renal transplantation is explained to patients who are diagnosed with ESRD. One way to strengthen communication between doctors and patients would be to

provide standardized training to help improve their competency in communicating and counselling.

In keeping with other studies (Alvaro et al., 2008; Irving et al., 2011), the justification of next-of-kin and public to refuse organ donation is mainly due to their fear of organ donation for deceased and living-related renal transplantation as well as their cultural and religious belief. The public education system in Malaysia is critically inadequate to overcome this barrier of reduced organ donation rate (Tumin, Rasiah, et al., 2014). As a method to educate the public, a standardized syllabus on organ donation and transplantation (ODT) would be an excellent approach to help raise awareness of the younger population (Ha et al., 2016; Siebelink et al., 2017). Students who were taught ODT are extremely enthusiastic about it and had more discussions with their families at home, which would indirectly improve the adult's health literacy (Siebelink et al., 2017). Radical reform to public education of Malaysia would be necessary to incorporate ODT into schools' curricula as the key-informant suggested. It could be achieved by collaborating with religious authorities, healthcare professionals, and community organization to include values and relevant information into the syllabus that support ODT. In Japan, the incorporation of ODT into their national school systems have shown effectiveness. However, Akabayashi et al. proposed that more pro-active efforts are essential to involve the school children by using science and technology as a way for teaching and communicating (Akabayashi et al., 2018).

When discussing barriers to being present at the hospitals, key-informant suggested the RT services should be centralized to consolidate all services to improve pre-transplant evaluation. Formica et al. showed that by centralizing the pre-transplant workup, besides the significant reduction in the listing time for RT, the economic cost to the centre has also decreased considerably (Formica Jr et al., 2012). Likewise, Sultan and colleagues found that the delay in the pre-transplant process is mainly due to the workup being

conducted at their local dialysis centres, which may not be familiar with the pre-requisite testing resulting in longer waiting time for renal transplantation (Sultan et al., 2013). While addressing these barriers at the hospitals, key-informants suggested that an integrated system for renal transplantation service be arranged by coordinating with other supporting services to enhance the pre-transplant evaluation. As the central hub for RT, it would be an appropriate institution to engage experienced surgeons from private practice to train more transplant surgeons in the country. It would allow for future training of highly skilled transplant surgeons, and maintain a high quality and standard of renal transplantation practice in Malaysia (Bjazevic & McGregor, 2015).

The key-informants emphasized the importance of innovative ideas for recruiting organ donors for renal transplantation which would be sustainable. The discussion of incorporating the organ donation registration together with the driver's license application was proposed by key-informants. This approach is not something new. It has been widely practised in many countries like the United States of America (Rosenblum et al., 2012), United Kingdom (Rosenblum et al., 2012), Australia (Wakefield et al., 2011), Canada (Rosenblum et al., 2012), New Zealand (Rosenblum et al., 2012) and South Korea (Soyama & Eguchi, 2016). By partnering with the department of motor vehicles (DMV), it would provide the public with another alternative to register as an organ donor when they apply or renew their driver's license. Although other successful promotional campaigns focus on workplaces, college campuses and religious institutions in recruiting organs donors, but as Harrison and colleagues indicated, none of these programs were as successful in generating new donors when compared to the DMV campaign (Harrison et al., 2011). Rodrigue et al. support this finding because half of all organs procured in the United States are authorized through donor registries that administered by DMV with about 42% of all licensed drivers are registered as donors (Rodrigue et al., 2014). One reason that the partnership with DMV was successful is because it reaches all the drivers

who are eligible donors and provides an avenue for immediate registration as donors. To complement this approach, providing financially neutral acts to family members of deceased donors as a targeted campaign was suggested by key-informants. As Tumin and colleagues indicate, by providing a financially neutral situation for family members, they are more likely to consent for organ donation given the strong family cohesion in the society (Tumin et al., 2013).

Another approach suggested by the key-informant to mitigate the shortage of organ without converting to the "opting-out" system would be to allow kidney chain donation (KCD) or domino paired donation. KCD provides a solution to a patient who has a willing living kidney donor. However, in the KCD system, if the patient has an incompatible living donor then they could receive a compatible kidney from an altruistic donor (F. Butt et al., 2009). The classical approach of paired kidney donation has been successfully implemented in many countries such as South Korea (since 1991), United States of America (since 1998), Romania (since 2001), Netherlands (since 2004), and the United Kingdom together with Australia (since 2007) (Chkhotua, 2012; Johnson et al., 2008). Many restrictions limit the application of this approach such as geographical and legal barriers that Gentry et al. have resolved using innovation such as expanding the number of participants in the scheme and relaxing the rules regarding reciprocity (Gentry et al., 2009). KCD would not just expand the donor pool but also provide high-quality donor organs, in contrast to organs procured from extended criteria donors and donation after cardiac death donors (F. Butt et al., 2009). There is a need for the transplant community to move beyond the old paradigm so that it will make an impact on the morbidity and mortality of ESRD patients waiting for suitable kidneys. It can be achieved through the cooperation of various transplant centres. Besides that, KCD would positively impact these transplant centres by improving their consistency and fairness in organ allocation.

Montgomery and colleagues have demonstrated that KCD has the capacity to enhancing the quality and the number of RT (Montgomery et al., 2006).

5.3 Association of Socioeconomic Status on Waiting Time to Renal Transplantation

The total number of patients awaiting renal transplantation in Malaysia has been continuously soaring because more than 1000 patients go on to develop the end-stage renal disease (ESRD) every year (Bujang et al., 2016). The assumption made was that the patients who were on dialysis because of signs and symptoms of ESRD would be a good indicator for placement on the waiting list for renal transplantation. Hence, the Researcher defined the access to renal transplantation as the duration of waitlisting from dialysis initiation to renal transplantation for all renal transplant recipients from 2002-2011. Using nationally obtained longitudinal study data from the National Renal Registry, ReTRAPP was able to demonstrate that the role of socioeconomic status (SES), particularly for household income. It considers the confounding of patients' age, gender, ethnicity and geographical location, is associated with the access to renal transplantation in Malaysia.

Overall, the findings from ReTRAPP demonstrate that the access to renal transplantation between the highest and lowest SES groups are comparable. As a result, it conflicts with most studies that were conducted in the United States of America (Axelrod et al., 2010; Stolzmann et al., 2007), United Kingdom (Udayaraj et al., 2010), Sweden (Y. Zhang et al., 2018) and Australia (Grace et al., 2013). According to Axelrod et al., who used an SES index score that was adopted from the Agency for Healthcare Research and Quality to categorize the 203,267 patients in the national registry into different SES levels based on their scores (Axelrod et al., 2010). Among the factors used

for this scoring were median household income, college education and employment, among other factors. The study demonstrated that living renal transplant was 15% more in the highest SES patients when compared to the lowest SES category within three years of listing for renal transplantation. This association remained even after adjusting for confounders with an increase to 75% likelihood of transplant for high SES compared to the lowest strata (adjusted HR = 1.76, 95%CI: [1.70-1.83]). Similarly, a longitudinal study using the UK Renal Registry adopted the Townsend Index to determine community-level SES as a proxy for individual-level SES (Udayaraj et al., 2010). Udayaraj demonstrated that lower rates of deceased renal transplantation were associated with low SES (adjusted HR = 0.59, 95%CI: [0.54-0.65]) (Udayaraj et al., 2010). This suggests that studies conducted in high-income countries demonstrated an SES gradient disparity when it comes to access to renal transplantation.

Kihal-Talantikite et al. conducted a retrospective longitudinal study in Bretagne, France. He demonstrated that the access to transplantation after placement on the list is not associated with the higher SES (Kihal-Talantikite et al., 2016). Kihal-Talantikite's study also utilized the socioeconomic deprivation index to categorize the neighbourhood of the patients. In this index, education, income, occupation and unemployment were factors that were used to calculate the index (Kihal-Talantikite et al., 2016). It shows that patients living in advantaged neighbourhoods (reference group) have an almost similar waiting time for renal transplantation compared to patients living in moderate deprived areas (adjusted HR = 1.14, 95%CI: [0.9-1.4]) and in low deprived areas (adjusted HR = 1.04, 95%CI: [0.8-1.3]). The explanation provided by some researchers was that SES neighbourhood index is not the deciding factor but operates as proxy for access to renal transplantation because the patients in lower SES neighbourhood would be more likely to suffer from more chronic diseases (e.g. diabetes mellitus, coronary artery disease,

cerebrovascular disease, etc) and have poor nutritional status leaving them unsuitable for renal transplantation during the assessment (Kihal-Talantikite et al., 2016; R. L. Morton et al., 2015).

The findings from ReTRAPP have shown that patients with secondary-level educational attainment and RM1000 – RM3000 household income have a 21% and 33% longer waiting time for renal transplantation respectively compared to the highest SES groups of tertiary-level educational attainment and >RM 3000 household income. To understand this disparity, the dichotomy healthcare system practised in Malaysia must be appreciated. It provides complete coverage for renal transplantation services to all citizens regardless of their SES, and this drives the healthcare system to achieve outcomes similar to other high-income countries. However, under this system, the intermediate SES group benefit from both the public and private healthcare system because they can finance their renal care by either out-of-pocket payment or through medical insurance (Yu et al., 2006). Due to the affordability of the public healthcare system, the healthcare facilities are overwhelmed with a large number of patients leading to a long waiting period. As a result, the intermediate SES groups (secondary educational attainment and intermediate household income) would seek care at private healthcare facilities while maintaining their medical follow-up at the public healthcare facilities. The use of both healthcare systems by the RTRs may have affected their care because the two systems are functioning independently without any integration of information and expertise. If the access to the dual healthcare system is harmonized with public-private collaboration, it will improve access to care, quality of service delivery, efficiency and patient outcome (Ng et al., 2014).

The majority of the highest SES group would prefer to use the private healthcare system. In contrast, the lowest SES group such as primary-level educational attainment,

household income of <RM 1000 and unemployed groups would generally seek healthcare from the public healthcare centres (Ministry of Health Malaysia, 2015; Yu et al., 2006). The comparable waiting-time of these RTRs to highest SES groups demonstrates that the public healthcare system has provided affordable and accessible quality care to the RTRs.

It was noted that RTRs who were outside workforce were 45% more likely to access renal transplantation faster than patients who were employed in Malaysia. From the socio-demographic characteristics, the RTRs in the outside workforce subgroup consists of homemakers, students and retirees with a majority of RTRs being female (69%), married (75%) and having at least a secondary educational attainment (75%). The Researcher hypothesizes that the higher number of females in outside workforce subgroup compared to secondary educational attainment (38%) and intermediate household income (37.1%) subgroups contributed to the utilization of healthcare services more readily than male patients. It confirmed what is already known in the literature, which demonstrated that females were reported to have higher healthcare-seeking behaviour than men (M. T. Lim et al., 2019; Thompson et al., 2016). The educational attainment level of the RTRs in the outside workforce subgroup is high (75% have at least secondary educational attainment). The findings from this study indicate that the educational attainment level (access to renal transplantation similar between highest SES and lowest SES groups) does not correlate with the health literacy of the RTRs. Further research is needed to study the relationship of health literacy amongst the RTRs and access to renal transplantation.

For countries with a publicly funded healthcare system like the United Kingdom and Malaysia, the problem of the uninsured seeking care would not arise because everyone would have universal health coverage. Although United Kingdom has the National Health Service (NHS Blood and Transplant), disparities in SES for access to renal transplantation were demonstrated by Udayaraj et al. Under the NHS, renal

transplantation assessment is usually centralized at regional transplant centres rather than local dialysis centre which delays the process of referral and assessment (Udayaraj et al., 2010). As for Malaysia, any credentialed nephrologist would be able to assess the ESRD patient and place the patient on the transplant list without having to go to the transplant centres.

One of the key elements that differentiates ReTRAPP from other published studies in high-income countries is their reliance on neighbourhood-level or community level SES as a proxy for the individual-level SES characteristics. The outcome from these analyses using neighbourhood-level SES could be considerably weaker when compared to individual-level SES measures because of misclassification of the individual SES (Pardo-Crespo et al., 2013). The demographics of people in the community may vary significantly in terms of ethnicity, employment opportunities and educational attainment within the geographical boundary. Undoubtedly, Malaysia, as a multiracial and multicultural country, would have a very heterogeneous distribution of people within a specific geographical boundary. Therefore, ReTRAPP addressed this argument of heterogeneity of the patients by measuring individual-level SES instead of neighbourhood-level SES as a proxy.

5.4 Association of Socioeconomic Status on Post-Transplantation Survival

With the advancement of medical science in organ preservation such as improvement in surgical techniques, immunosuppressive therapy, and post-operative services in the hospital have resulted in the survival rates of renal transplant recipients exceeding 90% at one year and five years post-transplantation (Gaston, 2016; H. S. Wong & Goh, 2018). In this sizeable RTR-based study, increasing socioeconomic status (SES) was associated with better survival rates. There was a statistically significant increment in the hazard ratio for mortality in the educational attainment subgroup (adjusted $P_{Trend} < 0.001$) for renal transplant recipients (RTRs) from 2002-2012. This association between SES and the post-transplantation survival rate was independent of age, gender, ethnicity and geographical location. However, household income (adjusted $P_{Trend} = 0.056$) and employment status with (adjusted $P_{Trend} = 0.215$) did not show any statistical difference in the likelihood of mortality within the stratification.

There is overwhelming evidence that SES such as educational attainment, household income and employment status influence the survival rate of RTRs. For instance, Petersen et al. conducted a retrospective longitudinal study using data from the United States Renal Data System demonstrated a strong and independent association of RTRs employment status with patient's survival rate (Petersen et al., 2008). However, utilizing employment status information alone would not be representative of the RTRs because returning to employment is associated with post-transplantation (Eng et al., 2012). In the USA, RTRs who are under the coverage of Medicare (government-run insurance program) would only receive immunosuppressive therapy for three years post-transplantation (Axelrod et al., 2010). As a result, these RTRs would need to seek employment to maintain their coverage of immunosuppressive therapy when the Medicare benefits terminate.

Furthermore, under the Medicare policy, RTRs would need to pay 20% of the medication cost by out-of-pocket (OOP) payments which may lead to poor compliance with medication and a risk of higher mortality compared to RTRs on private insurance who pay substantially lower in OOP payments (Goldfarb-Rumyantzev et al., 2006). For RTRs who are unable to get employment were more likely to be noncompliant to the immunosuppressive therapy once the insurance coverage end. Another study by Mistretta et al. corroborated this hypothesis by demonstrating that those who with skilled occupation (adjusted HR 0.13, 95%CI: [0.03-0.57]) were at a lower risk of mortality compared to unemployed (reference) (Mistretta et al., 2009). It was suggested that RTRs with lower SES would have lesser access to quality healthcare and be less informed on post-transplantation care leading to poorer health (Mistretta et al., 2009). However, this is the opposite of Malaysia, which provided universal health coverage to all its citizens in the country. RTRs who are unemployed would still be able to access quality public healthcare facilities that are heavily subsidized by the government by paying RM 5 (~USD 1.2) at each follow-up appointment at the specialist out-patient clinic and be supplied with immunosuppressive medication. It could explain the comparable risk for mortality of the employed RTRs (reference) with the unemployed RTRs (adjusted HR 1.15, 95%CI: [0.64-2.07]). It must be mentioned that the Ministry of Health implemented a policy that restricts the subsidized coverage of immunosuppressive therapy to RTRs who resorted to transplant tourism in 2012 (Director-General of Health Malaysia, 2011). However, this policy does not influence the findings of ReTRAPP because the data was collected before the enforcement of the policy.

The initial hypothesis of ReTRAPP that lower SES would be associated with worse post-transplantation outcome was in part accurate, with educational attainment and household income showing SES disparities. However, it was observed that the RTRs with

tertiary educational attainment (reference) have higher survival rates compared to primary educational attainment (adjusted HR 0.50, 95%CI: [0.34, 0.73]). It showed a statistically significant trend for P-Value. One possible inference is that RTRs with lower educational attainment might have poor awareness of their post-transplantation care (compliance with medication, regular follow-ups for outpatient clinic appointments, and communicate with healthcare professionals). It may be due to their limited health literacy (Driollet et al., 2019). Schaeffner et al. suggest that the poor compliance to immunosuppressive medication might be the reason for RTRs with lower education attainment to have worse transplant outcome (Schaeffner et al., 2008). The household income showed no statistical significance to the post-transplantation outcome (adjusted trend for P-Value = 0.056). However, there was a noticeable disparity between the RTRs with the highest household income bracket (reference) having a higher survival rate compared to lowest household income (adjusted HR 0.71, 95%CI: [0.48, 1.05]). It ties back to RTRs with lower SES, namely low household income having a higher risk for more inadequate health literacy (Chisholm-Burns et al., 2018).

In studies similar in design to ReTRAPP, which used data from a UK registry (Begaj et al., 2013) as well as from the Australian and New Zealand registry (Grace & McDonald, 2013) yield a similar outcome. The findings from Begaj showed that at five years post-transplantation, the RTRs living in the least socioeconomic deprivation (adjusted HR 0.65, 95%CI: [0.54-0.77]) had a higher likelihood of survival than RTRs living in most socioeconomic deprivation neighbourhood (reference) (Begaj et al., 2013). It was comparable with the study from Australia (adjusted HR 0.71, 95%CI: [0.55-0.92]) (Grace & McDonald, 2013). In these studies, neighbourhood-level characteristics were adopted, which contains income, education and employment deprivation as some of the domains. It was mentioned by Begaj et al. that RTRs living in the socioeconomically

deprived neighbourhood are at risk for higher mortality. It may be due to a lack of social support system and their intrinsic behaviour for unhealthy lifestyle practices such as smoking, alcohol consumption, poor diet and sedentary lifestyle (Begaj et al., 2013). However, Axelrod et al. described the use of neighbourhood-level SES as a significant limitation because it misclassifies the determinant of SES at a community-level instead of the individual-level. This support the use of more individually defined characteristics of SES rather than reliance on a broad neighbourhood domain.

ReTRAPP results are in contrast with those reported in two other studies from France (Kihal-Talantikite et al., 2016) and Scotland (Aitken et al., 2013), which have universal health coverage via national health insurance, showed that the SES of RTRs is not associated with post-transplantation survival. Both these studies used neighbourhood-level deprivation score rather than individual-level deprivation, which showed no difference in overall mortality rate post-transplantation in the lowest SES deprivation neighbourhood compared to the highest SES deprivation neighbourhood. These studies demonstrated that post-transplantation disparities in SES are generally associated with other post-operative outcomes (Lowrance et al., 2010; E. J. Morris et al., 2011) or survival rate of chronic diseases (Addo et al., 2012; Hawkins et al., 2012; O'Connor & Wellenius, 2012) that was not evident following renal transplantation and post-transplantation survival. However, few studies (Axelrod et al., 2010; Garg et al., 2011; Mistretta et al., 2009) have gone beyond the clinical determinants and attributed the association of low SES to poor survival due to the poor adherence to RTRs medical follow up. Poor compliance to their immunosuppressive drug therapy, reduce access to a broader spectrum of healthcare services, and the difference in organ quality that was not adequately adjusted for in the multivariate analysis.

As mentioned previously, the majority of the studies conducted on RTRs survival rates were from high-income countries with a better healthcare system and more advance quality of care compared to low and middle-income countries. The main challenges faced by the low and middle-income countries were mainly due to inadequate funding, poor organizational structure, an inadequate workforce, unavailability of new technology, lack of ancillary services and poor access to newer immunosuppressive medication (Akoh, 2011). Even though access to affordable healthcare service is unrestricted in Malaysia, RTRs might still lack self-care behaviour and less likely to be compliant to their immunosuppressive drug therapy and medical follow up leading to high risk of mortality.

5.5 Association of Socioeconomic Status on Post-Transplantation Quality of Life

The concept of Quality of Life (QOL) of a patient goes beyond morbidity and mortality of the disease. It is the patient's perception of multidimensional aspects that concern the patient's physical, psychological and socio-ecological well-being (Patrick & Chiang, 2000). QOL is increasingly recognised as an essential measure to evaluate renal replacement therapies. Numerous studies have proven that renal transplantation markedly improves the QOL when compared to other renal replacement therapy modalities (Fujisawa et al., 2000; H. Lim et al., 2016; M Tonelli et al., 2011; Wyld et al., 2012). Although renal transplantation improves the renal transplant recipients (RTRs) survival and QOL, it remains a chronic illness, in which RTRs requires lifelong medical follow-up and immunosuppressive therapy. Like any chronic medical conditions (Mielck et al., 2014), socioeconomic status (SES) plays a leading role in determining the QOL of patients. SES is an essential factor associated with patient's QOL through various mechanisms (Sesso et al., 2003); behavioural or lifestyle patterns that affect health, access to health services and healthcare financing. SES characteristics (e.g. educational level, household income and employment status) usually serve as confounders, but many studies do not show the associations between SES and QOL (Mielck et al., 2014).

Due to scarcity of studies especially in low- and middle-income countries that assess the interference of SES in the QOL of RTRs, this study was conducted to confirm that the indicators of SES are important factors associated with the QOL of RTRs. SES would influence how RTRs perceived their quality of life after renal transplantation. One example to demonstrate this hypothesis is that when each of the WHOQOL-BREF domains showed a statistically significant difference to the socioeconomic gradient of educational attainment and household income (P-Value <0.05). It indicates that the higher the educational attainment or household income, the better they perceived their physical

health, psychological health, social relationship and the environment they live and work compared to lower SES groups. Furthermore, looking at the multivariate analysis after adjusting for age, gender, ethnicity and geographical location, all the WHOQOL-BREF domains were statistically significant towards educational attainment and household income (except for the social domain) of RTRs. There is a statistically significant increment in the difference for all WHOQOL domains for the educational attainment (adjusted P_{Trend} <0.01) and household income (adjusted P_{Trend} < 0.01) to confirm this finding.

Alketheri et al. conducted a study that looked into the QOL of 357 RTRs and 461 liver transplant recipients in Riyadh, Saudi Arabia. The study confirmed the findings of ReTRAPP that showed a socioeconomic gradient towards their perceived WHOQOL domains for educational attainment, economic status (household income) and employment status (Alkatheri et al., 2015). Another study conducted in Sao Paulo, Brazil investigated the effects of SES (defined as educational attainment, ownership of domestic appliances and housing characteristics) on ESRD patients' QOL using SF-36 also yield similar findings of patients with lower SES who presented with worse QOL than those of higher SES (Sesso et al., 2003). Furthermore, a similar study was conducted by Malekahmadi et al. (2011) in Tehran, Iran but on 55 adolescents showed that education and family income was a significant variable that affects the QOL of adolescent RTRs. It must be known that by comparing different QOL measuring tools may produce similar statistical results but may yield discrepancy in interpretation (Fiebiger et al., 2004). However, these studies, to a certain extent substantiate the present ReTRAPP study to indicate that RTRs of lower SES would fare worse QOL than those with higher SES. These findings could be due to the inadequate access and use of healthcare facility because of non-flexible employment (Gulliford, 2017), poor compliance to

immunosuppressive drug therapy (Kapoor et al., 2015) and lack of social support network (Chisholm - Burns et al., 2010). All of these are associated with individuals with low SES would exacerbate adverse QOL. However, QOL depends on the RTRs life from the moment in which it is evaluated, but the WHOQOL survey does assess the RTRs characteristics and long-term needs.

However, it is interesting to note that, employment status of RTRs was only statistically significant for two domains of WHOQOL which were the physical health (adjusted trend for P-Value = 0.004) and social (adjusted trend for P-Value = 0.022). While for psychological health and environment domains, a lack of statistical significance was noted, whereby the RTRs who are outside the workforce present better QOL instead of those who are employed. The subgroup of individuals outside workforce represents the elderly who are retired, home-makers, and students who consciously opt to be excluded from employment possibilities by pursuing a particular course that prevents them from entering the labour force. In the Asian culture, the financial support for these individuals especially the home-makers and students would traditionally fall on the patriarchal breadwinner of the family (Kelan, 2008; Sacristan) while the retirees would generally have their retirement fund or pension to support them (Asher, 2012; Moorthy et al., 2012). It removes the burden to provide for the family in the outside workforce subgroup of individuals, which will most likely contribute to better psychological health and surroundings compared to the employed subgroup.

Furthermore, the employed individuals will have a double burden of health impairment as well as providing for their families, leaving them vulnerable for psychological distress. The environmental aspect of WHOQOL has a component of neighbourhood facilities that attribute to QOL and correspond to services and socioeconomic features of where RTRs lives. RTRs in the employed subgroup would

generally lack the opportunity to experience these facilities because of their time spent at work as compared to outside workforce subgroup.

Healthcare providers must understand more about what life is like post-transplantation to inform better and support RTRs. Although renal transplantation dramatically improves QOL, some segments of the RTRs population still do not benefit as significantly as the others. ReTRAPP was able to demonstrate that QOL and SES may be significantly associated and that the measurement of QOL of RTRs would be misrepresented if SES is not taken into account. As a whole, ReTRAPP has shown that the RTRs with low SES generally seem to be more disadvantaged with lower levels of valuated QOL when compared to RTRs with high SES. The use of the WHOQOL survey allowed ReTRAPP to determine which QOL domains generally influence the condition of RTRs. The overall QOL score differences between the SES gradient allows the improvement in preventative, therapeutic, and rehabilitative care by the healthcare providers by focusing on life domains that RTRs consider to be important. It would be recommended that the association between SES and QOL be considered a measurement in all future studies of QOL in patients with chronic disease; such as RTRs because by assessing the relative role SES of QOL. It would encourage healthcare professionals to look beyond medical treatment and concentrate on these group of RTRs more following transplantation for a better outcome.

5.6 Association of Socioeconomic Status on Post-Transplantation Financial Burden

This study illustrates the burden of post-transplantation care on renal transplant recipients (RTRs) attending outpatient clinics at public tertiary healthcare facilities in Greater Kuala Lumpur. To the best of the Researcher's knowledge, this is the first significant study to conducted in a low and middle-income country examining the association of socioeconomic status (SES) of RTRs on their post-transplantation catastrophic health expenditure (CHE). The study of CHE is vital to measure equity in healthcare financing as well as the effectiveness of financial protection in achieving universal health coverage. More than one fifth (22.7%) of the RTRs who mostly reside in Greater Kuala Lumpur spent over 10% of their household income on post-transplantation care (direct medical expenditure). It is used as a CHE threshold in some of the previous studies conducted (Arsenijevic et al., 2016; Limwattananon et al., 2007; Loganathan et al., 2015; O'donnell et al., 2008; Raban et al., 2013). This amount of spending on healthcare may lead to reduce household expenditure on essential items such as food items, clothing, and housing which may affect the quality of life of the family (Kawabata et al., 2002).

ReTRAPP provides insight into the determinants of CHE and impoverishment amongst RTRs visiting public tertiary healthcare facilities. CHE was measured as the direct medical cost at a 10% threshold of capacity to pay. The healthcare expenditure of total medical expenditure, which includes direct medical and direct non-medical cost. The characteristics of age and duration since transplantation for direct medical cost, the rest of the variables; ethnicity, marital status, geographical location, duration of dialysis, type of healthcare provider, household income, family or friend loan, reducing household spending, employer dividend fund financing and social security organization financing

were associated with catastrophic health expenditure for both direct and total medical cost. In both analyses of CHE for direct and total medical expenditure, RTRs within the higher household income have reduced odds of incurring the catastrophic expenditure. However, in the adjusted analysis, analysis of CHE for direct medical expenditure demonstrated a higher susceptibility for CHE compared to the analysis of CHE for total medical expenditure (compare table 4.33 and Appendix J). Therefore, the scope of ReTRAPP will only cover CHE post-transplantation through out-of-pocket (OOP) payment for direct medical expenditure.

All the participants (n=409) in ReTRAPP survey were recruited from six public hospitals in the Greater Kuala Lumpur which consist of two healthcare providers; four under Ministry of Health (MOH) and two under Ministry of Education (MOE). The public hospitals are funded by the Ministry of Finance via the Consolidated Revenue Fund (Kananatu, 2002). The hospitals under the MOE were privatized, and the subsidies for hospital fees were significantly reduced resulting in patients paying more (if not pensioners or government servants) than the hospitals under the MOH (RM 5 [~USD 1.2] for each appointment which includes medication). However, it is still below cost when compared to private hospitals (Quek, 2009; S. Thomas et al., 2011). In short, RTRs who are under the out-patient follow-up in MOE's hospitals would have a higher OOP payment compared with MOH's hospitals. From ReTRAPP, the rates of CHE were significantly higher for RTRs under the MOE's care at 63.4% compared to MOH's care at 36.6%. Nevertheless, RTRs under MOH's care suffer CHE, mainly because of the implementation to restrict the supply of immunosuppressive medications to RTRs who were suspected of transplant tourism. Hence, these RTRs have to resort to OOP payment to purchase the immunosuppressive medications required (Director-General of Health Malaysia, 2011).

As expected, the findings from ReTRAPP show that educational attainment and employment status does not affect the CHE of post-transplantation care of RTRs. Although the influence of lower SES often faces a higher likelihood of poor health outcomes, because they lack the financial capability to pay for appropriate and adequate healthcare services (Li et al., 2018). The RTRs were asked on how they cope with the OOP expenditure on their regular outpatient follow-up appointments and immunosuppressive therapy and the response of loan from family members or friends and reducing household spending was statistically significant with P-Value = 0.013 and P-Value = 0.002 respectively.

This research showed no statistically significant increment in the adjusted ratio for CHE in the educational attainment subgroup (adjusted P_{Trend} = 0.698) and employment status subgroup (adjusted P_{Trend} = 0.243). Lower educational attainment and unemployment are not associated with OOP payments in ReTRAPP. It is contrary to the association between SES and health expenditure that was discussed. However, this finding supports what has been reported by two published studies that shown no significant difference in educational attainment and employment status with CHE (J.-W. Choi et al., 2015; J. W. Choi et al., 2016). More importantly, ReTRAPP found significant increment of 4.7 times and 5.3 times for CHE for the Middle 40% household income category and Bottom 40% household income category respectively (adjusted P_{Trend} < 0.001). Generally, all RTRs will be able to access healthcare services at government facilities. However, the cost of healthcare may be a financial burden to the RTRs with lower income even when healthcare is subsidized in Malaysia. Previous studies conducting in developing countries like China, Indonesia and India have shown that government subsidies in healthcare benefited patients with higher income rather than the patients with lower income (Gwatkin, 2005; O'Donnell et al., 2007). Therefore poor

households were more likely to suffer CHE at any level compared to wealthier households (Wagstaff, 2002).

Xu et al. reported that CHE is common in several low-income countries, countries in transition and middle-income countries (Xu & World Health Organization, 2005). This negative impact of health systems on households that can lead to impoverishment has long been ignored on the health policy agenda. CHE is not a new problem, although it may be getting worse because Malaysia's public healthcare-service use has been expanding rapidly, with an increase of 15% in the utilization rate of public healthcare facility (Ministry of Health Malaysia, 2015). It could be explained by the high OOP payment at private healthcare facilities leading to the Middle 40% income subgroup seeking cheaper service at the public healthcare facilities. The findings from this analysis echo the problem of high OOP and CHE that is not limited to the Bottom 40% income subgroup but also the Middle 40% income subgroup. There is a need to ensure that these patients are protected against CHE when seeking post-transplantation care. The issue of CHE will not be solved with increasing household income. However, a change in the healthcare financing policies to effectively pool the financial risk of healthcare expenditure and narrow the gap in socioeconomic inequity.

5.7 Strength and Limitation of ReTRAPP

5.7.1 Introduction

ReTRAPP study has several important strengths and limitations which will be discussed based on the different study design. It begins with the qualitative component followed by both the quantitative components; retrospective longitudinal cohort study, and multi-centre cross-sectional study.

5.7.2 Perceived Barriers and Solutions to Renal Transplantation in Malaysia (Objective 1)

5.7.2.1 Strengths

There are some advantages of using key informant in-depth interview in ReTRAPP. First and foremost, key informant's opinion and experiences produce an expert-level perspective that gives contextual insight into the issue being researched (Pope et al., 2002). This method was relatively easy and inexpensive to conduct (Green, 2001; Runciman, 2002) but allowed the researcher to understand the situation of renal transplantation in Malaysia profoundly and in detail. The qualitative approach to data collection allowed ReTRAPP to explore new and previously undocumented perspectives on renal transplantation. The sample of key-informants was relatively diverse in terms of designations and their role in the renal transplantation process.

By using the socio-ecological model as a guide in ReTRAPP has allowed us to extract the barriers and the solutions of behavioural change and environmental enhancement in renal transplantation from the key-informants' experiences and perspectives. The multilevel analyses of individual, interpersonal, community,

organizational, and system offer qualitative evidence of the interplay in the renal transplantation process (Martin, 2013). It highlights the homogeneity of barriers to renal transplantation across diverse healthcare professionals and speaks to a shared understanding of the solutions to overcome them. Our findings show that key-informants were able to identify both barriers and solutions to the RT issues. Consistently, when key-informants identified barriers, they also provided complimentary solutions to solve the problems.

5.7.2.2 Limitations

While this study provides a solid look into the insights of key-informants' perceptions of renal transplantation in Malaysia, there are some limitations to the study. It is important to note that the findings were derived from clinicians, policymakers, researchers with a focus on renal transplantation. However, by using these purposive sampling, it ensured that the recruitment of key-informants encompassed the broad cross-section of experts involved in the renal transplantation system in Malaysia. The researchers are aware that the themes and subthemes may not be exhaustive of all the potential barriers and solutions to renal transplantation because the key-informants interviewed were all medical practitioner. So ReTRAPP was unable to cover the non-medical personnel's (e.g. RTRs, kidney donors, family members) perspective on renal transplantation.

The principal researcher who was engaged in conversation with the key-informants may risk introducing biases into the conversation during the interview. Additionally, the influence of the researcher as an integral part of the interview process brings inherent biases to evaluation and analysis of the information provided cannot, therefore, be

excluded (Giacomini et al., 2000). However, every attempt was made by the researcher to avoid leading the interviews with the key-informants by having a standard key interview guide for all interviews.

5.7.3 Association of Socioeconomic Status on Access to Renal Transplantation and Post-Transplantation Survival (Objective 2 & 3)

5.7.3.1 Strengths

To the knowledge of the Researcher, this study appears to be the first to assess non-medical features of the renal transplant recipients in Malaysia using the information from the National Renal Registry. This study also appears to be the first to investigate the socioeconomic status of ESRD patients on the access and outcome of renal transplantation in Malaysia and lower- and middle-income countries. The availability of follow up data allows ReTRAPP to estimate the waiting time to renal transplantation and post-transplantation survival, which is crucial to answering the research question.

The utilization of secondary data from the National Renal Registry of Malaysia has many advantages. The main benefit would be that the registry already exists, and therefore there would not be any additional time and cost attributed to the ReTRAPP study. The database from the registry encompasses all the renal transplant recipients in Malaysia, which will allow for better precision in analysing exposures and outcomes of interest because of their large sample size and representativeness of the target population. Besides the cohort study of the renal transplant recipients, which provide insights into changing population demographics and their health outcomes, registry data are collected independently of the ReTRAPP study limiting certain biases such as non-response bias associated with the one-time survey.

5.7.3.2 Limitations

In ReTRAPP, several limitations were identified based on the study design of the retrospective longitudinal cohort study. One of the limitations of this study was the use of secondary data from 2002 – 2016 and that the data was extracted from the registry, which may not be able to answer the research question. A common predicament faced with using secondary data would be the possibility of having missing data which will be detected by the Researcher by routine data exploration or data cleaning. To maintain the confidentiality and privacy of participants in the registry, not all data were made available to the Researcher for analysis. Furthermore, the data collected by the registry was voluntary and at times may not have a complete dataset for all patients in the system.

One of the major limitations of using secondary data from the National Renal Registry would be the completeness of the information. High missingness was observed for dependent and independent variables required for analysis. To overcome it, the missing data for the variable of interests in the dataset was dealt with using multiple imputation. Additionally, the follow-up and quality of information in the registry were unverified, which is crucial for the integrity of the dataset. Another limitation of using secondary data would be that the data collection form was not designed by the Researcher analysing the data which will lead to the ununiform interpretation of the data set (Cheng & Phillips, 2014).

5.7.4 Association of Socioeconomic Status on Post-Transplantation Quality of Life and Financial Burden (Objective 4 & 5)

5.7.4.1 Strengths

Similar to the quantitative component using secondary data from National Renal Registry, the multi-centre cross-sectional study of ReTRAPP appears to be the first to investigate the financial burden of renal transplant recipients in Malaysia using the catastrophic health expenditure approach. Furthermore, the health-related quality of life using the WHOQOL is stratified with the socioeconomic status of the renal transplant recipients to provide a broader understanding of the social determinant of health in renal transplantation. Apart from adopting a validated scale whenever possible to minimize resources, the financial burden survey was to suit the local context.

Before data collection at the study site, the surveys were validated and translated for the local population. Since all the transplant centres are located in the Greater Kuala Lumpur area, the demographics of renal transplant recipients was not just restricted to Kuala Lumpur but also from across Malaysia, which provides a more representation of the Malaysian population. The data collection was performed by the Researcher, who ensures that the instruction to all participants to administer the survey is standardized. Additionally, the rapport built by the Researcher with the renal transplant recipients at the outpatient clinic contributed to a relatively high response rate of 75%.

5.7.4.2 Limitations

For the other quantitative component using multi-centre cross-sectional survey, the most common limitation is that the study is not longitudinal and there would be no follow up to monitor the trend (socioeconomic status) in the outcome over time (Sedgwick, 2014). While it would only be able to highlight an association between socioeconomic status and renal transplantation outcome, but it may not determine the causal pathways because this can only be achieved by using a prospective study. Additionally, the survey was conducted in Greater Kuala Lumpur (885 RTRs) only and may not be generalizable to the RTRs population in Malaysia (1888 RTRs). Moreover, ReTRAPP surveyed public hospitals where many services are subsidized for renal transplant recipients, and the degree of expenditure is likely to be more in private healthcare facilities.

As with any self-reported research study, information obtained from participants are referenced as self-reported data. A consistent limitation in this study was collecting sufficient and validated data for the survey, especially for the financial expenditure of the participants. Furthermore, recall bias may be a contributing factor in causing participants to recall their household income and expenditure in the past month. There might be some element of non-response bias (Berg, 2010) because previous studies have demonstrated that respondents reported better health status compared to non-respondents (Cheung et al., 2017). It indicates that individuals with more inferior health status would not participate in a health survey.

CHAPTER 6: CONCLUSION

The concluding chapter would summarize the key study findings and the implications for policy and practice. Furthermore, the policy brief presented in Chapter 6.3 would drive the practice of applied research by promoting recommendations based on ReTRAPP study. Following the brief, the subsequent sections include the recommendation for prospective research and concluding remarks.

6.1 Summary of Key Study Findings

ReTRAPP provided some understanding and insight into the renal transplantation system in Malaysia from qualitative and quantitative approaches; with data being collected via in-depth interviews with key-informants, self-administered survey and secondary data from the National Renal Registry to answer the research questions. The following sections review each research objective and provide conclusions based on the study findings, which are related to it.

6.1.1 Objective 1: To describe key-informants' perception of the barriers and solutions to access renal transplantation in Malaysia

Key-informants were selected because of their expertise in the renal transplantation system. The key-informants have a desire for improved practices of the renal transplantation process in Malaysia to facilitate higher transplantation rates in the existing system. The in-depth interviews were able to identify a complex interplay of personal, cultural, and environmental factors (Hod & Goldfarb-Rumyantzev, 2014) that are affecting the renal transplantation system in Malaysia.

This emphasizes that barriers to renal transplantation access are multifactorial and many of these factors engage in different levels related to recipients, donors, community, healthcare providers and the healthcare system. Guidance for developing culturally competent interventional strategies was elicited from the key-informants to tailor future policies effectively that will improve renal transplantation rate and services in Malaysia. Key-informants emphasized the need to improve the promote the effectiveness of renal transplantation by educating patients, families and the wider community. The key informants also recognised the importance of supporting renal transplantation as the optimal renal replacement therapy as well as a system that encourages renal transplantation as the preferred renal replacement modality.

6.1.2 Objective 2: To examine the impact of socioeconomic status on access to renal transplant

Looking at the access to renal transplantation by renal transplant recipients' (RTRs), the retrospective cohort study from the National Renal Registry was developed to assess the SES of RTRs on the waiting time from end-stage renal disease to transplantation. There are disparities in access to renal transplantation based on the SES of the RTRs. There is inequality in the delivery of healthcare, whereby RTRs with secondary educational attainment had 21% (adjusted HR = 0.79, 95%CI: 0.67, 0.93) and RM1000 – RM3000 household income had 33% (adjusted HR = 0.67, 95%CI: 0.58, 0.79) lower hazards to access renal transplantation at compared to >RM3000 household income and tertiary educational attainment subgroups, respectively.

Lower levels of household income were associated with poorer access to renal transplantation (adjusted P_{Trend} = 0.001). The RTRs who are outside the workforce had a 45% (adjusted HR = 1.45, 95%CI: 1.21, 1.75) higher hazard of accessing renal transplantation compared to RTRs who are employed. The associations between waiting time to renal transplantation and educational attainment and employment status did not achieve statistical significance.

6.1.3 Objective 3: To determine the association of socioeconomic status on the survival of the renal transplant recipient

The cohort study looks into the RTRs' survival in Malaysia between 2002 and 2011. ReTRAPP was set out to determine the association of SES on the pot-transplantation mortality of RTRs. It was observed that there are disparities in the survival of RTRs across the socioeconomic gradient. RTRs with primary educational attainment had 102% (adjusted HR = 2.02, 95%CI: [1.38, 3.00]) and secondary educational attainment (adjusted HR = 1.69, 95%CI: [1.38, 2.31]) had 69% higher hazards of mortality compared to RTRs with tertiary educational attainment. Furthermore, a statistically significant trend for P-Value <0.001 indicates that the increasing level of educational attainment is associated with the increasing survival rate of RTRs. The associations between post-transplantation mortality and household income and employment status did not achieve statistical significance.

6.1.4 Objective 4: To evaluate the influence of socioeconomic status on quality of life among renal transplant recipients

The multicentre cross-sectional study was conducted using a validated WHOQOL questionnaire to assess the SES of RTRs on their quality of life (QOL). ReTRAPP confirms that SES is an essential factor that is associated with QOL in RTRs. RTRs who were more socioeconomic disadvantaged are associated with lower QOL scores in most of the WHOQOL domains. When stratified based on SES, higher educational attainment revealed better QOL scores for all the WHOQOL domains. The trend for P-Value for educational attainment also indicates statistical significance for all WHOQOL domains; physical (adjusted $P_{Trend} = 0.016$), psychological (adjusted $P_{Trend} = 0.002$), social (adjusted $P_{Trend} = 0.002$), environmental (adjusted $P_{Trend} < 0.001$), and the WHOQOL Overall QOL score (adjusted $P_{Trend} = 0.001$).

Similarly, for household income, higher-income indicates better QOL scores for all WHOQOL domains; physical (adjusted $P_{Trend} = 0.009$), psychological (adjusted $P_{Trend} < 0.001$), social (adjusted $P_{Trend} = 0.031$), and environmental (adjusted $P_{Trend} < 0.001$). Moreover, the trend for P-Value for household income was statistically significant for the WHOQOL Overall QOL score (adjusted $P_{Trend} <0.001$). Finally, the improvement in the QOL scores was only limited to the physical domain (adjusted $P_{Trend} =0.004$) and social domain (adjusted $P_{Trend} =0.022$) across employment status gradient. Furthermore, the association between the WHOQOL Overall QOL score and employment status was not statistically significant.

6.1.5 Objective 5: To compare the financial burden of renal transplant recipients according to their socioeconomic status

The financial burden of renal transplant recipients (RTRs) from the multicentre cross-sectional survey was estimated to be 93 RTRs (22.7%). The out-of-pocket payment that is significantly associated with catastrophic health expenditure is loans from family and friends as well as reducing their household expenditure. Household income was the only SES characteristic that showed a statistical significance to the prevalent odds of catastrophic health expenditure for post-transplantation care. The Middle 40% household income and Bottom 40% household income subgroups have 4.7 times and 5.3 times higher risk of prevalent odds for catastrophic health expenditure compared to the Top 20% household income subgroups. Lower levels of household income were associated with a higher prevalence for catastrophic health expenditure by RTRs for post-transplantation care (adjusted $P_{Trend} < 0.001$). The associations between the prevalence of catastrophic health expenditure and educational attainment and employment status did not achieve statistical significance.

6.2 Implication to Policy and Practice

Few studies were conducted to research on socioeconomic status (SES) for renal transplant recipients (RTRs), with all three classical characteristics of SES, which are educational attainment, household income and employment status. ReTRAPP addresses the research-practice gap in the renal transplantation system. First, it describes some challenges in the renal transplantation system and how to apply solutions to the practice of healthcare delivery. It then outlines the study of SES (educational attainment, household income and employment status) associated to renal transplantation and how it to allow policymakers to have a better understanding of the implications of SES as a social determinant of health in current medical practice.

RETRAPP's qualitative research of perceived barriers to renal transplantation in Malaysia was limited and paled in comparison with quantitative data. The research explored the multilevel challenges faced in the Malaysian healthcare system. The recommendation put forth by the key-informants is aimed at targeted problems elicited during the in-depth interviews. As such, the provisional findings of the qualitative data have significant implications for the development of a culturally acceptable and appropriate policy for renal transplantation in Malaysia. The publication and presentations of the findings would represent the academic dissemination, the primary dissemination of the findings to inform good practise and improvement in policy would be via a policy brief to the Ministry of Health as the leading healthcare provider.

Overall, the quantitative results of ReTRAPP have demonstrated the value of considering SES as an indicator of access renal transplantation and the RTRs' health post-transplantation. The findings from ReTRAPP have significant policy implications because it underscores the disparities in the access and outcome to renal transplantation. It demonstrated that the RTRs in the intermediate SES subgroups have poorer

accessibility and post-transplantation outcomes compared to RTRs in the highest SES groups. The potential problems of SES, which is associated with the access renal transplantation and the post-transplantation outcome may stem from the poor communication between renal transplant recipients and the healthcare providers. Communication is the foundation of a good doctor-patient relationship that could improve the delivery of care and the patient's health. Healthcare providers are encouraged to understand and address social factors that affect health outcomes during pre- and post-transplantation care. For better-valued health outcomes, daily function for prevention and inequitable access to care, a comprehensive approach focused on the immediate needs as well as the systemic issues is required. The healthcare providers need to ensure that the clinical decision-making in the renal transplantation process will consider the patients' SES as well as their preferences. Interdisciplinary collaboration between healthcare providers, support groups, social workers, and public health practitioners are essential in reducing the adverse health outcomes of RTRs related to social determinants, i.e. SES.

As is so often the case, awareness may be the most essential and most effective recommendation. The failure to translate research into the delivery of care is usually the most common finding in most health-related research (Fiebiger et al., 2004). Nevertheless, the translation of knowledge from researchers to practitioners in the health system is vital to promote the health of RTRs. It has been a driving force of RETRAPP to conduct modifiable practice-oriented research with a health perspective. All stakeholders must be made aware of the possible negative impact of low socioeconomic status on RTRs in Malaysia's healthcare system. Healthcare leaders must recognize the importance of social determinants in the delivery of care and routinely review the delivery policy of the population served to ensure the sustainability of the health system. Healthcare providers should understand the workings of the social determinants of health

and approaches to manage RTRs whose health is influenced by their SES. It highlights the importance of SES and the underlying individual, community, and systemic issues related to health inequities by integrating it into health education at all levels. It provides an opportunity to improve the overall health of the RTRs.

ReTRAPP underpinned the importance of public-private partnership in the delivery of post-transplantation care as well as prevention of chronic kidney disease in the population. With the high cost of renal replacement therapy and the morbidity as well as mortality associated with ESRD should prompt the policymakers to shift the focus on primary and secondary prevention of chronic kidney disease (mainly precipitated by diabetes mellitus and hypertension)(Harris et al., 2019). The partnership between the Ministry of Health Malaysia, Malaysian Society of Nephrology and National Kidney would create awareness about the risks of kidney disease and promote the early detection, treatment and management of it. This collaboration will allow the sharing of information and resources to improve patients' outcome better.

Besides that, ReTRAPP emphasized the need for a better healthcare financing policy for the renal transplantation program in Malaysia as well as post-transplantation care financing for the vulnerable RTRs who are at risk of catastrophic health expenditure due to out-of-pocket payments. With the competing demands for limited healthcare funds, a resource for renal transplantation would not be a significant priority. Learning from Singapore on public-private partnership, Malaysia may adopt the practice of policies implementation that acknowledges and support private contributions, as well as revision of healthcare laws to encourages private entities to participate in the provision of renal transplantation services (Morad et al., 2015). It will not just improve the healthcare financing but also encourages community participation and create awareness of chronic kidney disease.

6.3 Policy Brief

The study findings and policy recommendations are summarised in the policy brief entitled; “Removing Barriers in Kidney Transplantation: Action Needed to Improve End-Stage Kidney Disease Patients’ lives”. The policy brief is illustrated in Figure 6.1, Figure 6.2, Figure 6.3, and Figure 6.4.

policy brief

02/20

UNIVERSITY OF MALAYA

Removing Barriers in Kidney Transplantation

Actions needed to improve end-stage kidney disease patients' lives

Author: *Peter Gan Kim Soon, University of Malaya*

Soaring rate of chronic kidney disease should translate to accruement of kidney transplantation. However, only a small number of patients undergo transplantation as their initial modality of renal replacement therapy. This figure is mostly unchanged depite the high numbers of end-stage kidney disease patients (refer Figure 1). This policy brief provides an overview of key issues as well as the effect of the social determinant (i.e. socioeconomic status) on kidney transplantation. It focuses primarily on kidney transplantation in Malaysia, which would be relevant to clinicians, policymakers, civil society and academia of low- and middle-income countries facing a similar predicament.

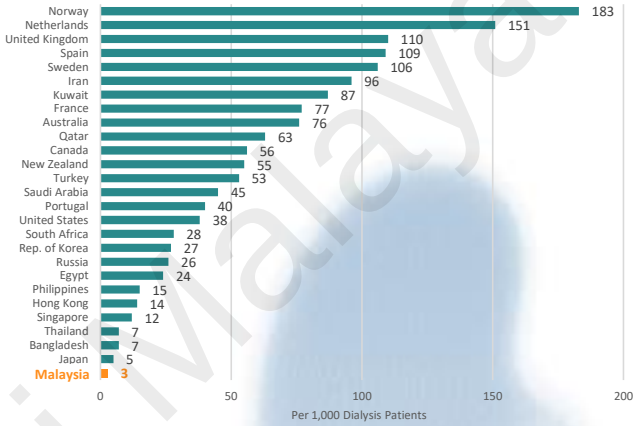


Figure 1 Kidney transplantation rate per 1000 dialysis patients, by country, 2015

Source of data: Saran et al. (2018)[1]

Social Determinants of Health

"Conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems. It is responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries."

Source: World Health Organization
https://www.who.int/social_determinants/sdh_definition/en/

What is the issue?

Many studies in high-income countries have been conducted on the barriers to kidney transplantation and the social determinants to access and outcome of kidney transplantation.[2, 3] However, for low- or middle-income countries, it remains poorly understood because most of the studies conducted were focused on medical treatment-related factors, while the complex interplay of personal, cultural, environmental and system-related factors are still not well explored in the health system.

Kidney transplantation may not be a priority in low- and middle-income countries due to the lack of resources (e.g. infrastructure and workforce) and the survival of the kidney transplant recipients can be complicated by the accessibility and affordability of immunosuppressive drugs, and infectious disease.[4] The role of social determinants (i.e. socioeconomic status) on kidney transplantation is complex because it affects healthcare provision and uptake along the pathway to transplantation. Nevertheless, kidney transplantation should be the modality of choice promoted by the government to treat end-stage kidney disease.

As Malaysia inches closer to achieving high-income nation status, there is a need for more locally relevant research to allow policymakers and clinicians to make an informed and evidence-based decision. The implications of this research could prompt a policy change for a better health service delivery model on par with other high-income countries. By providing information on disparities to access kidney transplantation and in the delivery of post-transplantation care, it is expected that this brief will benefit clinicians, policymakers, civil society, and academia in Malaysia and beyond.

1

Figure 6.1 Policy brief (page 1)

About the research

This brief is based on the research project – ReTRAPP, which provides evidence on the issues in kidney transplantation in Malaysia. Although considerable literature exists on kidney transplantation in high-income countries, significant knowledge gaps can be found in relations to kidney transplantation in low- and middle-income countries, especially in Malaysia. ReTRAPP attempts to respond to it with the following questions:

1. What are the barriers and recommendations to access kidney transplantation in Malaysia?
2. What is the impact of socioeconomic status of kidney transplant recipients on access to renal transplant?
3. What is the association of socioeconomic status on the survival of the kidney transplant recipient?
4. What is the financial burden of kidney transplant recipients according to their socioeconomic status?
5. What is the influence of kidney transplant recipients' socioeconomic status on their quality of life?

The access and survival of kidney transplant recipients

The research determined the association of socioeconomic status and waiting time as well as post-transplantation survival of kidney transplant recipients. Instead of using community-level indicators of socioeconomic status, the research adopted the individual-level indicators to consider the heterogeneity of the kidney transplant recipients and to avoid misclassification.

Figure 2 demonstrates the socioeconomic characteristics associated with access to renal transplantation in Malaysia. This research found that disparity in household income was significantly associated with access to kidney transplantation. Besides, disparities were noted in the intermediate household income and secondary educational attainment subgroups with poorer access at 33% and 21% respectively compared to the highest household income and tertiary educational attainment.

Key findings from interviews with subject matter experts

Issues with access to kidney transplantation in Malaysia according to the socioecological model

Socioecological model	Barriers to access kidney transplantation in Malaysia[5]	Recommendations to improve access to kidney transplantation in Malaysia[5]
Individual-Level	• Donor's wish unknown to family member	• Educate organ pledgers to communicate with family members about their intention to donate their organs
Interpersonal-Level	• Bad perception of family member toward kidney transplantation • Family member refusal to donate the deceased's organ	• Ensure the living-related donors are aware that their wellbeing is looked after • Provide financially neutral situation to encourage organ donation
Community-Level	• Lack of awareness of organ donation and kidney transplantation • Non-communicable disease development leading to end-stage kidney disease	• Partner with community and religious leaders to foster support for organ donation and kidney transplantation • Promote organ donation and kidney transplantation benefits to the younger generation because they are more receptive • Encourage public to be healthy in order to prevent chronic kidney disease
Organization-Level	• Prolong waiting-time for pre-transplant assessment • Limited resources for kidney transplantation • Poor transplant literacy promotion to end-stage kidney disease patients • Priority for dialysis instead of kidney transplantation	• Improve waiting time by coordinating effectively with other departments for pre-transplant assessment • Recruit transplant experts from private practice to the transplantation service in public hospitals • Centralise the transplant centre to improve resource allocation and service • Train healthcare provider to educate patients on organ donation and kidney transplantation • Advocate stakeholder to prioritize kidney transplantation
System-Level	• Policy unfavourable to kidney transplantation • Inconsistent kidney transplantation promotion • Switching to opt-out system	• Revise the current transplantation policy and legislation in Malaysia • Incorporate organ donation and transplantation syllabus into the education system • Recruit new organ pledgers for organ donation during their vehicle license renewal • Explore kidney chain donation for endless recipient-donor pairings via a domino effect

2

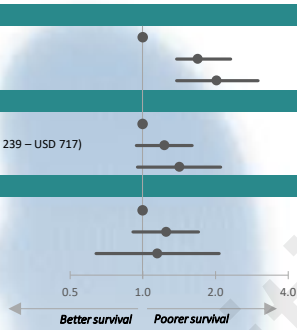
Figure 6.2 Policy brief (page 2)

Socioeconomic Status Characteristics	Adjusted HR (95% CI)	P-Value	P-Trend
Educational Attainment			0.474
Tertiary	1.0 (reference)		
Secondary	0.79 (0.67, 0.93)	**0.006***	
Primary	1.00 (0.80, 1.25)	1.000	
Household Income			**0.001***
RM 3,000 (>USD 717)	1.0 (reference)		
RM 1,000 – RM 3,000 (USD 239 – USD 717)	0.67 (0.58, 0.79)	**<0.001***	
< RM 1000 (< USD 239)	0.80 (0.62, 1.04)	0.098	
Employment Status			0.089
Employed	1.0 (reference)		
Outside Workforce	1.45 (1.21, 1.75)	**<0.001***	
Unemployed	0.90 (0.65, 1.25)	0.522	

*Statistically significant

Figure 2 Association of socioeconomic status on access to kidney transplant

Socioeconomic Status Characteristics	Adjusted HR (95% CI)	P-Value	P-Trend
Educational Attainment			**<0.001***
Tertiary	1.0 (reference)		
Secondary	1.69 (1.38, 2.31)	**0.001***	
Primary	2.02 (1.38, 3.00)	**<0.001***	
Household Income			0.056
> RM 3000 (> USD 717)	1.0 (reference)		
RM 1,000 – RM 3,000 (USD 239 – USD 717)	1.23 (0.94, 1.60)	0.128	
< RM 1,000 (< USD 239)	1.42 (0.95, 2.10)	0.085	
Employment Status			0.215
Employed	1.0 (reference)		
Outside Workforce	1.25 (0.91, 1.70)	0.165	
Unemployed	1.15 (0.64, 2.07)	0.646	



*Statistically significant

Figure 3 Association of socioeconomic status on kidney transplant survival

Although the survival rate of kidney transplant patients in Malaysia is comparable to other high-income countries,[5,6,7] disparities between the socioeconomic gradient is evident from the findings of the research (refer Figure 3). Educational attainment is the only characteristic that is significantly associated with post-transplantation survival. Primary educational attainment has 2 times the risk for mortality compared to tertiary educational attainment. While secondary educational attainment is 69% more likely to die compared to tertiary educational attainment.

Household income and employment status showed a decline across the socioeconomic continuum but was not statistically significant. The crucial finding of the current research is that socioeconomic inequality plays an important role in post-transplantation survival.

Catastrophic Health Expenditure (CHE)

"When people have to pay fees or co-payments for healthcare, the amount can be so high in relation to income that it results in "financial catastrophe" for the individual or the household. Such high expenditure can mean that people have to cut down on necessities such as food and clothing, or are unable to pay for their children's education."

Source: World Health Organization
https://www.who.int/health_financing/documents/pb_e_05_2-cata_sys.pdf

Financial burden of kidney transplant recipients

Kidney transplant recipients experienced financial burden when their out-of-pocket medical-only expenditure is above the 10% household income. Even small out-of-pocket payments may cause financial burden for kidney transplant recipients with household income in the Bottom 40% and Middle 40%.

As anticipated, the research validates what we already know about the disparity in out-of-pocket payment across the household income continuum. The prevalence of catastrophic health expenditure is 5.3 times higher among the Bottom 40% household income and 4.3 times higher among the Middle 40% household income compared to the Top 20% household income (refer Figure 4). The research highlights that socioeconomic disparity plays an important role in the incidence of CHE.

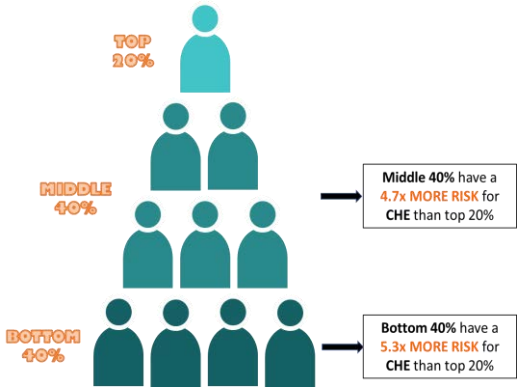


Figure 4 Association of household income on financial burden

3

Figure 6.3 Policy brief (page 3)

Quality of Life (QOL) of kidney transplant recipients

The association of socioeconomic status with the quality of life was conducted using the WHOQOL survey that captured 4 domains; physical, psychological, social and environmental aspect of the kidney transplant recipients. Comparison between the domains is made by transforming into a scale from 0 to 100 for each domain.[9]

The research showed that the quality of life kidney transplant recipient varies between the socioeconomic gradient. Those who were more socioeconomic disadvantaged in educational attainment, household income and employment status were associated with lower quality of life in all the WHOQOL domains (refer Figure 5). The overall QOL illustrated that socioeconomic disparity was found to have an impact on the QOL of kidney transplant patients.

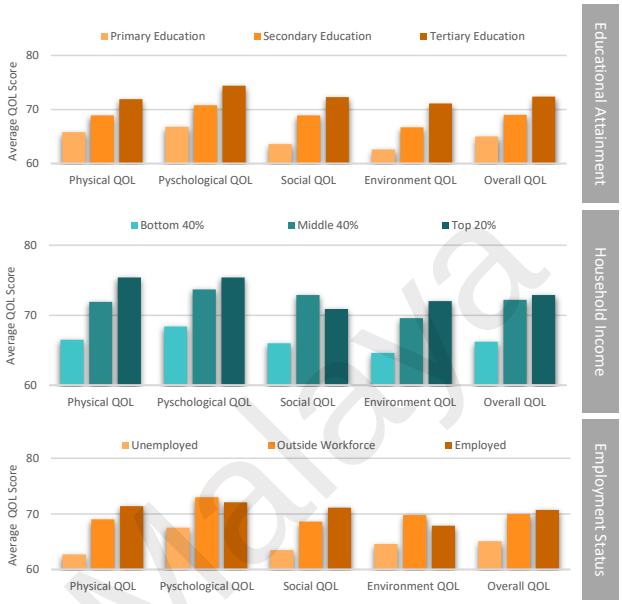


Figure 5
Association of socioeconomic status on quality of life

What should be done?

The research raised awareness of the effect of social determinants on the kidney transplantation system. In order to ensure better-valued health outcomes and daily function for the prevention and inequitable access to care, a comprehensive approach focused on the immediate needs as well as the systemic issues is required.

The barriers and recommendations elicited from subject matter experts explore the multilevel challenges faced in the Malaysian healthcare system. As such, the provisional findings underscore the disparities in the access to kidney transplantation and have significant implications for the development of a culturally acceptable and appropriate policy for kidney transplantation in Malaysia.

Policymakers must recognize the importance of social determinants in the delivery of care. Healthcare providers should understand the workings of the social determinants and approaches to manage kidney transplant recipients whose health are influenced by their socioeconomic status. It highlights the importance of socioeconomic status and the underlying individual, community, and systemic issues related to health inequities by integrating it into health education at all levels.

Public-private partnership is essential in the delivery of post-transplantation care and the prevention of chronic kidney disease in the population. It will help create awareness about the risks of kidney disease and promote the early detection, treatment and management of it.[10] At the same time, private entities participating in the provision of care will contribute to the financing of kidney transplantation services. This partnership will allow the sharing of information and resources to improve patients' outcome better. Public-private partnership will ensure effective delivery, better efficiency and affordable costs that will ease the burden on the public healthcare system.[11]

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Figure 6.4 Policy brief (page 4)

6.4 Recommendations for Prospective Research

From this series of studies, ReTRAPP was able to suggest that researchers are better informed about targeting SES in renal transplantation. The positive effect of individual-level SES on access to renal transplantation and the post-transplantation outcome could be used to guide future research on disparities in other renal transplantation outcomes. The use of broader social determinants such as health-literacy, degree of urbanization, disability status, internet access, ownership of appliances and immigration status (Gordon et al., 2010) or the broader conceptualization of SES by Agency for Healthcare Research and Quality (Axelrod et al., 2010) could help establish a better understanding of the social determinants of health for RTRs.

Another approach to study the association of SES would be to extend the cross-sectional survey across the country. It would provide a more holistic understanding and generalizability of renal transplant recipients' SES on the access and outcome of renal transplantation in Malaysia. As studies examining access and outcome of renal transplantation rarely consider healthcare providers' perspective, future studies may include them for a more holistic understanding of the situation, which may help improve the healthcare services delivery.

One key component that was missing in the ReTRAPP study was the RTRs' health literacy. A prospective study should include the association of RTRs' health literacy and how it affects their healthcare-seeking behaviour concerning chronic kidney disease and renal transplantation. The ways that RTRs interact with the healthcare delivery system may lead to the development of behavioural interventions designed to optimize how RTRs access the health system. This added information would help and policymakers and clinician to improve the development of an appropriate intervention to the RTRs by

increasing targeted awareness of chronic disease prevention and available transplantation services.

Factors within the multilevel socioecological model of influence have been highlighted in the qualitative research influencing access to renal transplantation in Malaysia. Following ReTRAPP, therefore, future research will include more prospective studies exploring other stakeholders' perception of renal transplantation in a Malaysian setting and how targeted interventions improves the renal transplantation rates and affect the stakeholders. There is a need for more regional collaborative partnerships and interdisciplinary qualitative research to address the barriers to access renal transplantation in low- and middle-income countries.

6.5 Concluding Remarks

ReTRAPP was conducted to predominantly assess the social inequalities in the population of RTRs in Malaysia as well as explore the barriers that limit the rate of renal transplantation. Specific barriers and solutions highlighted in ReTRAPP, such as the perception towards organ donation and the opt-out system of organ transplantation indicate a need for policy change in the health service delivery model.

The findings of ReTRAPP indicate that RTRs with lowest SES receive similar or better opportunity compared to RTRs with highest SES to access renal transplantation in Malaysia, they have a higher risk for post-transplantation mortality. Under the Malaysian public healthcare system, healthcare is heavily subsidized by the government and the RTRs with lower SES would not have any problem to access affordable and quality healthcare at any nearby public healthcare facilities. Despite the comprehensive post-transplantation care of the RTRs provided by the public healthcare facilities, however, the healthcare system is unable to cope with the increasing patient volume and the burden of non-communicable diseases in the community. As demonstrated by the more inadequate access to transplantation with the intermediate SES groups as well as poorer outcomes across the socioeconomic gradient, a public-private collaboration for the provision of care should be considered to ensure effective delivery, better efficiency and affordable costs as well as to help ease the burden on the public healthcare system (Morad et al., 2015; Ng et al., 2014).

Socioeconomic disparities were observed in the access and outcome (survival rate, QOL, and CHE of RTRs) of renal transplantation in ReTRAPP. SES, as a social determinant of health, will influence the health outcomes of RTRs and ultimately achieving health equity. Some considerations of the social determinants of health in the

healthcare setting are in practice. However, a more robust integration into the delivery of healthcare should be considered. The direct participation of multisectoral stakeholders is necessary to gain a better understanding of how social determinants of health will influence the health system and the policy decision-making that proceeds it. Presently, with better communication between healthcare providers and RTRs, social determinants could be identified and managed effectively through early and continuous education as well as research on health disparities and adverse health outcomes.

Problems of disparity affect people on a daily basis, and has detrimental effects on the larger society today, tomorrow and in the future. As Malaysia inches closer to achieving high-income nation status, there is a need for a paradigm shift to consider social determinants of health in the renal transplantation process. The implications of this research could prompt a policy change for a better health service delivery model on par with other high-income countries. By providing information on disparities to access renal transplantation and in the delivery of post-transplantation care, it is expected to benefit clinicians, policymakers, civil society, and academia in Malaysia and beyond.

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LIST OF PUBLICATIONS AND PAPERS PRESENTED

Publication

1. A qualitative examination of barriers and solutions to renal transplantation in Malaysia: Key-informants' perspective (Manuscript published in PLOS One)

PLOS ONE

RESEARCH ARTICLE

A qualitative examination of barriers and solutions to renal transplantation in Malaysia: Key-informants' perspective

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Abstract

Introduction

End-stage renal disease (ESRD) is increasing globally, and renal transplantation (RT) is the preferred renal replacement therapy to treat ESRD. Internationally, there are only a few countries with RT rates above 50 per million population (pmp), while most of the countries have RT rates between 30–40 pmp. The low- and middle-income countries (LMIC) makes up the majority for the RT rates below 20 pmp in which Malaysia belongs to despite its increasing ESRD rates. There is a need to explore the barriers to access RT with targeted solutions to improve the RT rates and service in LMIC. Thus, a qualitative study was undertaken in Malaysia to address this issue.

Method

A qualitative methodological approach was performed between March-May 2018. Semi-structured interviews were used to explore current RT policy and service availability. Key-informants were identified from a detailed stakeholder analysis of RT system in Malaysia. Interviews were digitally audio-recorded, transcribed verbatim, coded with ATLAS.ti software and underwent thematic analysis thoroughly.

Results

Eight key-informants participated in the study. Barriers and related solutions were classified using the socio-ecological model (SEM). As reported, the barriers and solutions of RT in Malaysia are the results of a complex interplay of personal, cultural, and environmental factors. Key barriers are linked to public's attitude and perception towards RT and the unaccommodating practices in the healthcare fraternity for RT. Key-informants provided a systematic solution that shed light on how RT could be improved at each SEM level via effective communication, education and inter-agency collaboration.

Publication

2. What are the barriers and solutions to renal transplantation in Malaysia? A qualitative key-informant study (Abstract published in Malaysian Journal of Medicine and Health Science)

Malaysian Journal of Medicine and Health Sciences Vol.15 Supp 6, October 2019 (eISSN 2636-9346)

What are the Barriers and Solutions to Renal Transplantation in Malaysia? A Qualitative Key-Informant Study

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ABSTRACT

Introduction: Kidney transplantation (KT) is the preferred end-stage renal disease (ESRD) treatment because it pro-vides a better survival rate, quality of life as well as a cheaper alternative. However, Malaysia's KT rates is consis-tently low considering that ESRD rates have been increasing exponentially. With only four hospitals performing KT, there's a gap to indicate a lack of evaluation in KT system of Malaysia. Qualitative study was undertaken to explore and describe the barriers and solutions improve the rates and service of KT in Malaysia. **Methods:** Semi-structured interviews adopted as qualitative methodological approach to explore current KT policy and service in Malaysia be-tween March – May 2018 in Kuala Lumpur. Eight key-informants selected using stakeholder analysis and informed consent were obtained. Interviews were digitally audio-recorded, transcribed verbatim and analysed using thematic analysis. **Results:** Barriers and solutions of Malaysia's KT are the results of complex interplay of personal, cultural, and environmental factors that can be categorized and described using the five levels of influence conceptualized by the socio-ecological model (SEM). Guidance for developing culturally appropriate and sensitive interventional strategies was elicited from the key informants' experiences to improve KT rate and services in Malaysia. **Conclusion:** Malaysia is experiencing very low rate of KT compared to other countries. The use of SEM provided a framework to foster a better understanding of current practice, barriers and solutions to KT in Malaysia. Implications of these find-ings could prompt policy change for better KT service delivery model. Further stakeholder engagement and evalua-tion is required to align best practices to improve KT rates and service in Malaysia that is comparable to high-income countries.

Keywords: Renal transplantation, Access, Key-informants, Qualitative study, Low- and middle-income countries

Publication

3. Impact of socioeconomic status on access and outcome of kidney transplantation in Malaysia (Abstract published in Malaysian Journal of Medicine and Health Science)

Malaysian Journal of Medicine and Health Sciences Vol.15 Supp 6, October 2019 (eISSN 2636-9346)

Impact of Socio-Economic Status on Access and Outcome of Kidney Transplantation in Malaysia

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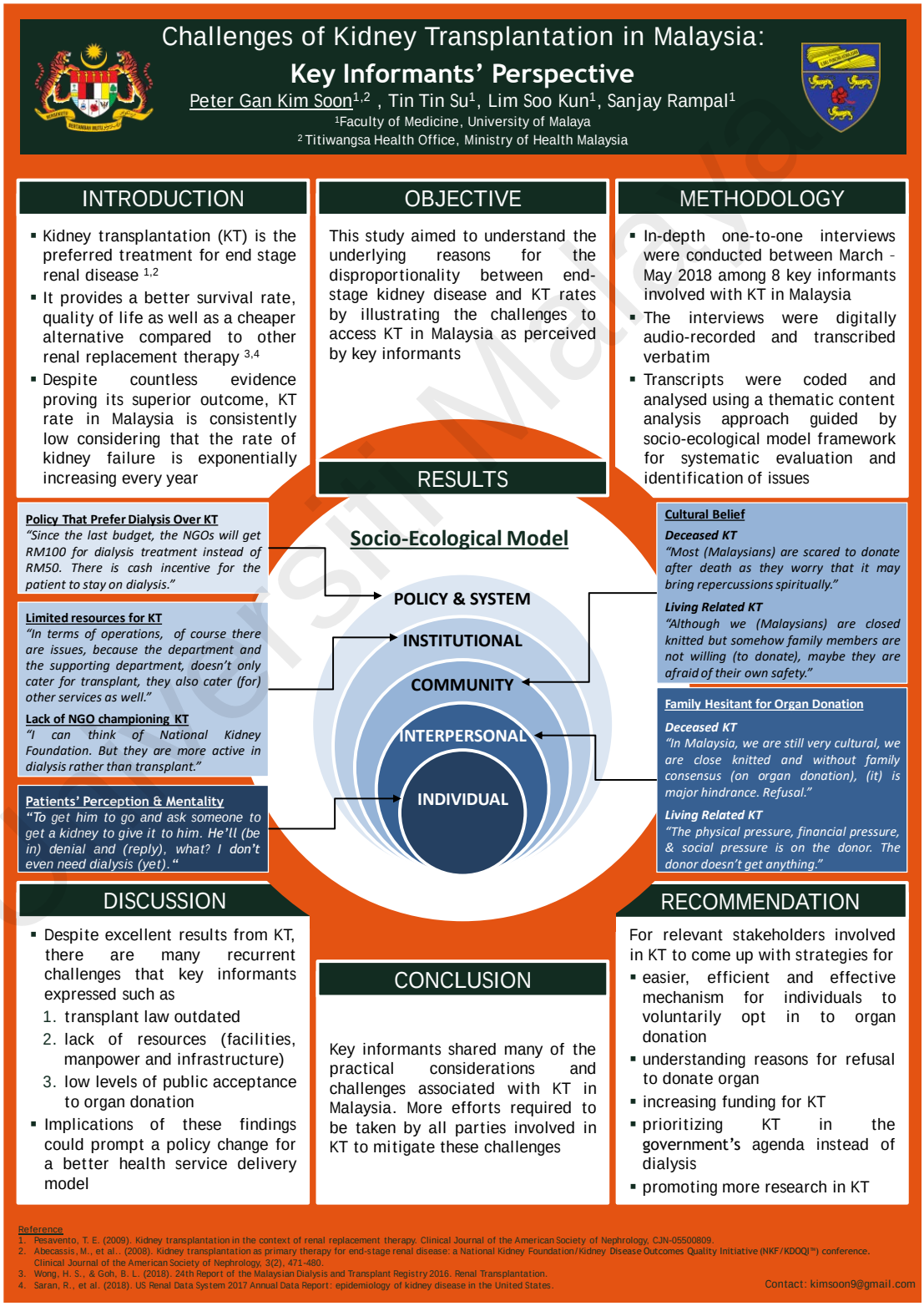
ABSTRACT

Introduction: Low socio-economic status (SES) has been associated with poorer access and worse outcome in kid-ney transplantation (KT) for high-income countries. In contrast, relatively little is known about the KT access and outcome between the socio-economic gradient in Malaysia, which is a low- and middle-income country. The aim is to determine the association of SES with access and outcome of kidney transplantation in Malaysia. **Methods:** We examined the Malaysian National Renal Registry for kidney transplant candidates listed between 2002 to 2011. Cox's regression was used to assess associations of SES with transplant access and outcome (survival). **Results:** 1234 patients were transplanted in 2002-2011 after excluding pediatric patients and multiple transplantations. The mean age of patients was 42.3 ± 12.3 years, 789 (63.9%) were male and 797 (65.0%) were of Chinese ethnicity. After multivariate adjustment, the primary education attainment group (adjusted HR=0.79, CI: [0.64, 0.97]) and lowest income group (adjusted HR=0.84, CI: [0.66, 1.08]) were more likely to access KT compared the other socioeconomic gradient. While patient with highest education and highest income were 50% and 29% more likely to survive respectively compared to patient with lowest education and income groups. **Conclusion:** Even in a healthcare system that is almost achieving universal health coverage, disparities exist in both extremes of the socio-economic gradient for the access and outcomes for KT in Malaysia. Reducing the SES disparities in KT will require policy initiatives addressing the components of SES (income, education, and employment) as well as the pathways by which this affect the health of KT patient.

Keywords: Socio-economic status, Disparities, Kidney transplantation, Access to transplantation, Waiting time

Presentation

1. Challenges of kidney transplantation in Malaysia: Key-informants' perspective (Poster presentation at the 50th & Golden Jubilee Conference of the Asia-Pacific Academic Consortium for Public Health 2018)



Presentation

2. Solving the issue of kidney transplantation in Malaysia: A stakeholder qualitative study (Oral presentation at the 12th annual Association of Pacific Rim Universities Global Health Conference 2018)
3. What are the barriers and solutions to renal transplantation in Malaysia? A qualitative key-informant study (Oral presentation at the 1st International Borneo Healthcare and Public Health Conference 2019)
4. Impact of socioeconomic status on access and outcome of kidney transplantation in Malaysia (Oral presentation at the 1st International Borneo Healthcare and Public Health Conference 2019)