SOCIO-ECONOMIC STATUS AND FINANCIAL BURDEN AMONG HEMODIALYSIS PATIENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA

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by

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CERTIFICATE

This is to certify that the dissertation entitled "Socio-economic Status and Financial Burden Among Hemodialysis Patients in Hospital Universiti Sains Malaysia" is the bona fide record of research work done by Ms. "Nur Fatin Aqilah Binti Mohd Fadzli" during the period from October 2020 to July 2021 under my supervision. I have read this dissertation and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation to be submitted in partial fulfilment for the degree of Bachelor of Nursing (Honours).

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DECLARATION

I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated and duly acknowledged. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at Universiti Sains Malaysia or other institutions. I grant Universiti Sains Malaysia the right to use the dissertation for teaching, research, and promotional purposes.

……

Nur Fatin Aqilah Binti Mohd Fadzli

Date: ……

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USM: Universiti Sains Malaysia

SPSS: Statistical Package for Social Science

CKD: Chronic Kidney Disease

HD: Hemodialysis

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STATUS SOSIOEKONOMI DAN BEBAN KEWANGAN DALAM KALANGAN PESAKIT HEMODIALISIS DI HOSPITAL UNIVERSITI SAINS MALAYSIA

ABSTRAK

Beban kewangan dalam kalangan pesakit hemodialisis adalah berbeza mengikut status ekonomi mereka. Perbezaan di dalam kadar pekerjaan, kelas pendapatan dan gaji bulanan menentukan di mana kelas bebanan kewangan untuk pesakit. Kajian ini adalah untuk mempelajari kesan sosioekonomi status dan beban kewangan dalam kalangan pesakit hemodialisis di Hospital USM. Kajian ini dilakukan menggunakan borang soal selidik secara kendiri dalam kalangan 100 peserta. Kajian ini dilaksanakan pada Oktober 2020 sehingga Julai 2021. Objektif umum bagi kajian ini adalah untuk mengetahui kesan status sosioekonomi dan beban kewangan dalam kalangan pesakit hemodialisis di Hospital USM. Tambahan lagi, kajian ini juga dilaksanakan untuk menentukan hubung kait antara status sosioekonomi dan beban kewangan dalam kalangan pesakit hemodialisis di Hospital USM. Analisis data yang digunakan ialah statistik deskriptif dan 'Ujian Pearson Chi Square' menggunakan 'Statistical Package of Social Sciences' (SPSS) versi 24.0. Keputusan menunjukkan majoriti daripada peserta mempunyai beban kewangan yang sederhana (n=52, 52%). Baki selebihnya iaitu beban kewangan yang rendah dan tinggi menunjukan keputusan yang seiring antara peserta. Kajian mendapati ada hubungkait antara status sosioekonomi (kadar pekerjaan, kelas pendapatan dan gaji) dan beban kewangan dalam kalangan pesakit hemodialisis di Hospital USM ($p > 0.05$ dan $p< 0.05$). Perbezaan status sosioekonomi dalam kalangan peserta menunjukan tidak semua orang mempunyai beban kewangan yang sama. Syukur, kerajaan memberi dana perbelanjaan untuk rawatan. Dana ini secara automatik mengurangkan beban mereka. Penyelidik mengharapkan agar kerajaan dan lebih banyak NGO memberi bantuan kepada mereka yang memerlukan. Inisiatif ini perlulah diteruskan kepada generasi hadapan.

SOCIO-ECONOMIC STATUS AND FINANCIAL BURDEN AMONG HEMODIALYSIS PATIENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA

ABSTRACT

Financial burden among hemodialysis patients were differed according to their socioeconomic status. Different in terms of employment rate, income class and salary determined which class of financial burden patients had. This study aimed to study the effect of socioeconomic status and financial burden among hemodialysis patients at Hospital USM. This study was conducted among 100 participants by using self-administrated questionnaire. It is conducted from October 2020 to July 2021. The general objective for this study was to study the effect of socioeconomic status and financial burden among hemodialysis patients in Hospital USM. In addition, this study also was conducted to determine the relationship of socioeconomic status and financial burden among hemodialysis patients in Hospital USM. The test used was descriptive statistics and Pearson's Chi Square test using Statistical Package of Social Sciences (SPSS) version 24.0. Results showed majority of the participants had moderate financial burden (n= 52, 52%). The remaining financial burden which are low and high had equivalent percentage of participants. There was a significant association of socioeconomic status (employment status, salary, and income class) and financial burden among hemodialysis patients in Hospital USM ($p > 0.05$ and $p< 0.05$). Different socioeconomic status showed that not everyone had the same financial burden. Thankfully, government had supported the fees for the treatment. The funding automatically reduces some of the burden of participant. Researcher hopes that government and more NGOs could lend their hands towards participant who needs it. This generosity should be carry on for the next generations.

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CHAPTER 1 INTRODUCTION

1.1 Background of Study

Worldwide, renal failure had become one of the burdensome diseases that affects many aspects in a person. One should have a very comfortable life without any diseases and promoting wellness at all ages. According to United Nations (World Health Organization (WHO), 2018), sustainable development goals (SDG) number three focusing towards health which is ensuring health lives and promotes wellbeing without any racism of ages and races around the world so that every person is treat equally. Stated by Norris, Williams, Nicholas and Agodoa (2017), kidney disease is categorized as non - communicable disease which leads to premature morbidity and mortality worldwide. Along with diabetes mellitus and heart disease, kidney disease is the most cause of the premature death in most countries (National Kidney Foundation (NKF), 2015).

NKF (2015) highlight that chronic kidney disease (CKD) was ranked 27th, caused of death back in 1990. But, in 2010, the number increases to 18th which we can see the trend is changing. More surprise is that, they predict that a greater number of kidney cases will increases in developing countries such as China and India as they have a lot of elderly in their country. It is proven that 10% from the population had diagnosed with CKD.

CKD is described as progressed impairment in kidney structure or function. Person is said having CKD if the kidney function is decrease to less than 10% (Goubin S., 2019). Although it may affect health function, it can be treated by frequently doing medical check at the nearest clinic. When a person had reached this stage, dangerous level of electrolyte, waste product and fluid may build up in the body (Sandhya, 2019). The usual nephrons able to receive extra work, but once it is broken over a year, a lot of

number of nephrons would be affected. At the certain points, nephrons that left unable to filter your body well thus it may danger your health. Notes that untreated kidney failure can be life-threatening.

Kidney function as the removal of the waste product or fluid that in excess in our body in the form of urine (NKF, 2015). It is also an organ that balance the fluids in the body. Unfortunately, a lot of people don't know the function of the kidney which make they didn't care about their kidney function. There's a lot of campaign and program done by the government to educate people on how to take care of their kidney from all ages. Luckily this disease can be treated or at least optimizing the function of kidney so that patient able to live their life at the fullest.

Need to remember that kidney disease may progress to kidney failure which make patient need to undergo dialysis or kidney transplant. Renal replacement therapies such as hemodialysis (HD) or peritoneal dialysis (PD). Although it is the treatment for CKD it also can become a cause of death. For example, those with CKD who receiving dialysis therapy have high mortality compared to healthy population (about 20% per year in US and 10-15% in Europe) primary due to cardiovascular disease (Abbot et al., 2016). Despite the poor prognosis for this, progress in the treatment and management for the patient improves the long-term outcome (Neild, 2017).

CKD is a progressing deterioration of kidney function over years. As define by The Renal Association on January 2021, CKD patient will have abnormalities in terms of function and structure of the kidney for more than 3 months. Some study states that CKD is progressive loss of function resulted from the injury at glomerular or tubular structure within the nephron and advances until the kidney cannot tolerate to function well anymore

or is a direct effect from a disease (Terrill, 2002). CKD was a curable yet preventable disease if it is managed well form the beginning of diagnosis (Johnson et.al, 2013).

The prevalence of CKD was estimated about 11-13% globally as stated by Caroline F. et. al, (2019). Then, CKD had affected almost 2 million people worldwide and the number of patients diagnosed with CKD is increasing at rate of 5-7% per year. This showed that although it's not the primary cause of death; the rate of patient will keep increasing if it is not treated well. We should understand that CKD can affect anyone irrespective the sex, race or age. Some countries had highest prevalence numbers of CKD when compared to others. Such countries are Taiwan, Mexico, Japan, Belgium, and United States. The mortality rates differ according treatment types. It was deciding that those on a dialysis will have mortality rate about 20%-25%, with a chance or 5% survival rate. after one-year treatment. But patient who undergoes kidney transplant have low mortality rate which is 3% (United State Renal Data System (USRDS), 2018).

Whereas the incident of CKD at Asian country stands about more than 14% of population. As asserted by Global Burden of Disease (GBD) recently, the CKD has ranked at 14^{th} in Asia much higher compared with another region globally. China alone has 119.5 million of CKD patients. These percentages were growing more in Asia because the increase rate of diabetes mellitus and hypertension cases. Every country had a catalyst factor on why the number of cases keep increasing.

Both China and Japan had tied in terms of prevalence and growing incidences of obesity and diabetes. It was also caused by increasing number of aging populations. But, in less developed South Asian, the prevalence of CKD said to be caused by risk factors of tuberculosis, diarrheal disease and infection by vectors. As these spots have limited access to healthcare equipment and treatment, nephrologists are limited, and medicine

sometimes are not available (Amess, 2018). In other study, the rate of annual growth was more than 10% which including country like China, Philippines, and Malaysia (Thomas, 2016). This is due to increase number of ageing populations, people with diabetes mellitus and hypertension (Lee, 2003).

Since this study will be conducted at Malaysia, it is important to relate the prevalence number to be the key indicator. Thus, according to Kidney International Reports study (Hirman et, al. 2019), prevalence of CKD in this country was 9.07% of total population. Which in this percentage, 0.36% are at stage 5 CKD or we called as an end-stage renal disease (ESRD). Corresponding to population-based study in West Malaysia (Hooi et al., 2013), the prevalence of CKD stage 1, 2, 3, 4 and 5 was 4.16%, 2.05%, 2.26%, 0.24% and 0.36%, respectively. Apart from that, 10 occurrences of ESRD patient are on dialysis had risen from 325 in 2001 to 975 in 2012 per million populations (Salman, 2016). The statistics proves that cases of CKD are progressing in such a short time.

There are various aetiologies that can cause CKD. United States had justified that diabetes mellitus or DM is the primary chronic disease that can cause CKD. Other study Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), 2011, state that in Australia diabetic neuropathy, hypertension and glomerulonephritis were common contributor to CKD. Both types of diabetes cause CKD (Chen, 2011) with its prevalence globally is 6,4%. This figure is projected to rise to 7.7% (439 million people) in 2030 (Vivek, 2013). Malaysia also state that number of CKD patient is progress due to high number of diabetes patient. As aging population is increase, number of chronic kidney disease increase (Ministry of Health Malaysia, 2018). Referring to Malaysia Dialysis and Transplant Registry data in 2015, 58% patient in Malaysia who undergoes dialysis is in 55 years and above. Poor control blood glucose level will eventually damage the

glomerular capillaries in the kidney thus leading to renal failure (Kidney Health Australia, 2014).

United Kingdom Renal Registry data back in 2011 listed that glomerular diseases accounts up to 16% from CKD patient at both UK and US country (Thomas et, al. 2011) condition such as glomerulonephritis. Glomerular diseases can be divided into 2 major categories, glomerulonephritis which describe the inflammation at membrane tissue of the kidney. Next is glomerulosclerosis which describe as the formation of scar or hardening of tiny blood vessels in the kidney (National Institute of Diabetes and Digestive and Kidney Disease, 2020).

Hypertension or HPT also can take the lead to CKD as it will damage the arteries surrounding the kidneys. Over time the arteries are either narrow, hardens or weaken that make these damaged blood vessels unable to deliver blood to the kidney efficiently thus making kidney necrosis. (American Heart Association,2016). As studied by to Horowitz, Miskulin and Zager (2015), both hypertension and kidney were interrelated with each other. The statistic showed that 30% and 15% most adult having HPT and CKD in US. Spain also reveals that prevalence of patient that have HPT in kidney disease is high as 60.5%. Yook and Siew (2013) concludes that adult patients in Malaysia who's having HPT have higher probability to develop CKD.

Generally, CKD is divided into 5 categories. This is depending on their GFR and the severity of albuminuria. Benjamin & Sarah (2020) as referred from Kidney Disease: Improving Global Outcomes (KDIGO) 2012 Clinical Practice Guidelines classified the staging to ease the physicians and other healthcare to promote suitable treatment and promote wellness.

Progression of kidney injury usually takes time. The kidney may undergo several stages before getting worst or malfunction. The worst scenario is that patient may have appeared asymptomatic (Benjamin & Sarah, 2020). Patient who have end stage renal failure have less ability to dilute or concentrating the urine effectively **(**Malkina A., 2020).

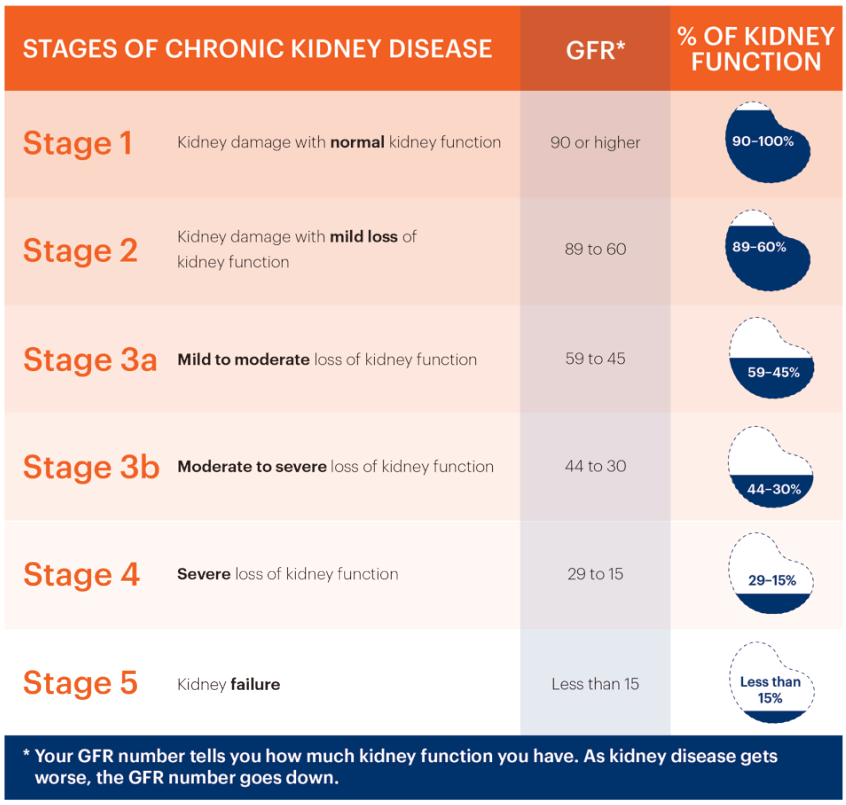

Figure 2.1: Stages in Chronic Kidney Disease by National Kidney Foundation

Patients with CKD usually asymptomatic in both stage 1 and 2. But if it is entering stage 3 patient may be experiencing nocturia. Anorexia can be seen. Patient will consistently be feeling tired all day long. Kidney Health Australia (2016) states that individual will lose up to 90% of their kidney function before symptoms become clearer. High blood pressure which alters the hemodynamic status also will be seen. Not only that, lack of concentration in doing daily activities may happen. Sometimes neurological system may affect such as seizures. Sometimes patient's general color is yellow- brown like jaundice patient, Pruritus can happen when the urea is crystalized and appear at the outer layer of skin.

In this study, researcher will study about how socioeconomic status effect the financial status for HD patient. Socioeconomic status differs among the participants. As in Malaysia complying three different income classes based on the salary, the impact for each category are different. HD is the treatment that filter waste product and water from the blood. It is also called as an artificial kidney as it applies the same function as the kidney. This treatment also helps in controlling blood pressure and balancing important minerals in our body so that hemodynamic can be reach at the optimum rate. Consistency in receiving HD lowering the chance of getting kidney transplant.

As stated by NKF (2015), HD usually performed 3 times in a week, it can be done at dialysis unit or at patient's house. Patient need to be educated and introduce the side effect of having a dialysis as it is slight costly. Overall treatment in a session also takes up to eight hours depending on the body size, current health state and amount of waste product (Brian, 2019). They also should be taught in strict treatment schedule, diet management and regularly taking medicines.

Having chronic health problems that is long-term used a lot of money. Health have been tied with economic growth. Different classes of socioeconomic status making each person have their own difficulty. Person with higher income tends to live longer as they able to get full access to health services. But patient in lower income must prioritize their financial usage for the most important event in their life. Unemployed person also having great impacts as they do not have definite source of income. They have high mortality rates (Frakt, 2018). The increase level of education also gives significant outcome in financial burden. For example, person who study at college able to prevent from getting illness as they knew the prevention measure of the illness (Gabriella et. al, 2018).

For example, according to Department of Statistics (2019), Malaysia had categorized the household income into three groups. This is based on the monthly income. Bottom 40 (B40) is the lowest rank which the household income had < RM 4,849. The second group in rank is Middle 40 (M40) which the income of their household > RM 8,700 but < RM 10,959. The highest rank is the Top 20 (T20). In this group, the income had exceeded RM 15,039 in a month. Based on this group, it is highlight that those in M40 and B40 may sustain greater financial burden in getting hemodialysis treatments. Person living in poverty is more than five times likely to have fair or poor health status compared to person who live in moderate income.

1.2 Problem Statement

As the worldwide becoming more modernized and develops, healthcare becomes one of the important aspects in delivering diligent and correct healthcare services. According to Pradeep (2020), global prevalence of CKD is 9.1% in 2017. 697.5 million cases of it reported from various stages. Due to increased number of CKD patient, HD

treatment become one of the options to reduce the progressiveness of the disease. But it is costly. Most people live in sedentary lifestyle cannot afford to continuing this treatment. Research states that Medicare had spent $35 billion in 2016 for renal patients. HD cost in average of $90,000 per patient annually in the United States, for a total of $28 billion. This showed those treatments is costly. In Malaysia, the number of patients uprising each year. It is estimated up to 7000 patients in a year. This made Malaysia the top seventh country with highest dialysis treatment rate in world (Yuen, 2017). It is stated by Hidayah (2019) 40,000 patient was undergoing dialysis treatment which we can see how important the treatment is.

Continuing the treatment monthly or yearly gives impact for these patients. The treatment of CKD or end stage renal failure is substantially high in cost. Patient needs to use a lot of money to make sure that they have complete sets of treatment in a session. It is including the transportation to go to clinic, HD apparatus and so on (Bender, Dykowska, Zuk, Milewska & Staniszewska, 2018). Cost for CKD not only focusing to dialysis apparatus, but also include non- health related facilities such as oral medications, non-renal health care as patient with cardiovascular disease and diabetes mellitus is one of the contributors to CKD.

Recent study states that, socioeconomic status played important role in financial status of a patient. Such socioeconomic status is employment rate, salary in a month or income classes according to their country. patients who have low level of education might have poor prognosis compared to high level one. Study by Rong Xu et al., (2012) said that poorer people have heavier burden to pay for medical expenses. Low individual income independently affected the health status as they couldn’t afford the fees for the treatment.

Most of study about financial impacts on hemodialysis patients were conducted among high, middle and low income countries (Neil, Walker, Sesso & Blackburn, 2017). Unfortunately, researcher only managed to find few published studied on financial burden of hemodialysis at Malaysia but there is no study for association between socioeconomic status with financial burden. Hence, these issues have motivated the researcher to conduct a study on effect of socioeconomic status and financial burden among hemodialysis patient who receiving treatment at Hospital USM.

1.3 Research Questions

1. What is the socioeconomic status among HD patients in Hospital USM?
2. What is the level of financial burden among HD patients in Hospital USM?
3. Is there any association between socioeconomic status (educational level, salary, employment status, income classes) and financial burden on HD patient in Hospital USM?

1.4 Research Objectives

1.4.1 General Objectives

The aim of this research is to study the effect of socioeconomic status and financial burden among HD patients in Hospital USM.

1.4.2 Specific Objectives

1. To identify socioeconomic status (educational level, salary, employment status, income classes) among HD patients in Hospital USM
2. To identify the level of financial status among HD patients in Hospital USM
3. To determine the association of socioeconomic status (educational level, salary, employment status and income classes) and financial burden among HD patients in Hospital USM

1.5 Research Hypothesis

The research hypotheses for this study were presented as below:

H^0: There is no significant association between socioeconomic status (educational level, salary, employment status and income classes) and financial burden on HD patient in Hospital USM

H^A: There is a significant association between socioeconomic status (educational level, salary, employment status and income classes) and financial burden on HD patient in Hospital USM

1.6 Conceptual and Operational Definition

Table 1.1 Conceptual and Operational Definition

Terms	Conceptual Definition	Operational Definition
Hemodialysis	Type of procedure that involving dialysis machine and a special filter called as an artificial kidney. This procedure is used to clean the blood. It is invasive procedure as doctors need to make an access into blood vessels so that blood able enter the dialyzer (NKF, 2020).	In this research, several patients who seeking hemodialysis treatment in Hospital USM will be chosen as participants. The selection is according to criteria that researcher had listed.
Financial Burden	Term that describing problems that patient has related to medical or non-medical cost. It may affect their health status and quality of life. For example, patient may not have access to health services as the fees is costly. They also may not seek for treatment even though they're in pain because they must save the money. The term	In this study, financial burden is referring to the population that have difficulty to continuing medical treatment, hemodialysis. The burden not only focusing on direct hemodialysis treatment but it also including non-direct treatments such as medication, the use of health appliances and so on

	also called as economic burden or financial hardship (National Cancer Institute, 2020). Bottom 40 (B40) is the lowest in income classes that had < RM 4,849. Middle 40 (M40) which the income of their household > RM 8,700 but < RM 10,959. These group were the most affected compared to Top 20 (T20) populations.	

1.7 Significance of Study

The significance of this study was not only towards patient, it also benefits for society, country, government, institution, and students. From this study, government may evaluate the characteristics of income for B40 and M20 family as these populations usually affected when it comes to money. In this study, government can conclude that despite patient knew the important of the treatment, they unable to seek it as they cannot afford to pay the fees. Thus, government should collaborate with non -government agency to create a fund to support not fully but maybe half from the medical fees. It will somehow lighten the burden that they have. Benefits from this study will also improve the knowledge for patients. This is because when there diagnosed with CKD they might got the information on what can they do and where they can ask for a fund. They also got an information about social welfare team that may fund them for treatment fees. Sometimes hospital also have their own welfare department, thus patient who having difficulty to pay the fees might have referred to that department. By this study also, patient and their relative having a right source for seeking reliable funding.

This is because physicians will provide other alternatives to treat CKD as they alert that HD is very costly. To achieve this, they need to do a lot of studies and experiments. From my point of view, the country able to generate latest tools on how to attract patient to undergoes treatment by doing free medical check-up, lowering the health bill and so on. For the society, as they knew that CKD patient cost a lot, they will take a good care for their health. They will highlight the important of good diet and annual medical check- up from themselves.

CHAPTER 2 LITERATURE REVIEW

2.1 Introduction

In this chapter, it will generally give the reader about the main idea or topics that is conducted by researcher. Literature review is a comprehensive summary about the past research that have been done at different countries or populations. The summary is taken from related articles, journals, books, and others relevant sources.

This chapter reviewing current literature related to socioeconomic status on financial burden among hemodialysis patient. It also highpoint the socioeconomic status such as employment status and income of a patient which could affect the financial burden among them. The comparison of statistics of patient on chronic kidney diseases in different countries and hemodialysis treatment also were done in this review.

2.2 Impact of Hemodialysis Treatment

2.2.1 The elements in socioeconomic status

Socioeconomic which comprised of family's or an individual's social position with others. The items include in this term is income of an individual, the level of education and the employment status (Townsend & Scriven 2014). Study in Iran said that low socioeconomic status may contribute to increase the rate of renal failure. This is because low level of education might affect the knowledge of a patient about the condition. Patient who had low income having health inequality because they didn't get full access to the healthcare service. They cannot afford to pay for consultation treatment nor to pay for the dialysis session. In low-income population, medical screening, and health promotion it not usually being held (Leila, Maryam, Arghavan & Mehrab, 2017).

Socioeconomic status in terms of educational level is that the highest education that a person had. Each person has different level of education, thus affecting on their attitude and perception about an issue. For example, person who had low level of education might have few information about the dialysis's cost and advantage. Gap difference between level of education in a person making that there is a better prognosis for high education person compare to the lower one.

Monthly income may be varied according to the position in the company, the years of serving in the job and the sector in which the person works for. Person who had high income might have less impact on their financial as they able to spend the salary. Income classification in Malaysia were divided into 3 categories which is based on the salary in the household. Need to remember that, it is not fixed as the term only providing the percentages of the populations. According to Department of Statistics (2019), Malaysia had categorized the household income into three groups. This is based on the monthly income. Bottom 40 (B40) is the lowest which the household income had < RM 4,849. The second group is Middle 40 (M40) which the income of their household > RM 8,700 but < RM 10,959. The highest rank is the Top 20 (T20). In this group, the income had exceeded RM 15,039 in a month. Based on this group, it is highlight that those in M40 and B40. The burden mostly affects the B40 population as they much likely had to pay more for the treatment.

2.2.2 The meaning of financial burden

Financial burden is used to describe problems a patient has that relates to the cost of healthcare. Not everyone has health insurance to cover the overall cost of medical treatment. it may increase the financial problems. Not having enough money also can be

defined as financial burden. There are few effects from having a financial burden. First, patient may have deteriorating in their quality of life since they might reduce the time for health check-up for saving their money. Second, the access to medical care is limited. This because since the price for treatment is high, they might be unable to continue the treatment despite their condition becoming worst (National Institute of Health, 2019).

Study by Freeman, Giles, Field, Halen and Sorstadius (2019), said that financial burden may include direct cost which including any intervention that patient went. The cost for resource utilizations and driver can be included in the terms. It is said that patient who had CKD had high usage of money compare to the one that having kidney disease stage three.

Finance is an important element when it is related to health-related factors. This socioeconomic status of patient will determine whether the treatment they're having will affect their financial or not over the year. As a healthcare worker, we should consider patient's financial status before determining the treatment for them. This is because not everyone has the same income or same amount of medical fees. In this study, we will look up if there is an association between socioeconomic status with financial burden among HD patients. The impacts from CKD will be explain later in terms of hospital care cost, HD treatment cost, transportation to hospital and pharmaceutical cost. It is stated that government in some countries had funded the cost of dialysis thus only few considers for the usage of their own pocket money to pay for medical expenses (Bello et al, 2018).

2.2.3 Association of socioeconomic status with financial burden

Globally, some countries may be able to pay for HD treatment fully based on their income. But there also incident where patient had to paid by themselves from pre dialysis and post dialysis treatment. For example, Minister of Health Jordan paid up half of the HD fees for their patient. The rest of fees will be pay by patients. Patient must pay from zero to 25% from total costs. As we knew, Jordan is a middle-income country which can classed in middle socioeconomic status. But, behind this status, a few of them unable to follow the treatment regime as they didn't have money to pay it. Standard treatment for HD is 3 sessions in a week, but patient more likely come for only once or twice (Eman, 2015). Based on Al Shdaifat and Manaf in 2017 reported that, there is direct nonmedical cost for every patient approximately about $2160 per year. Such nonmedical lists are transportation cost and time, over the counter medication, dialysis time, traditional medicines, and other personal equipment. Patients travel to hospital estimated 10 km and sometimes caregiver paid up the transportation fees. As the condition become worsen, the productivity of patient become loss. This including because they might quit their job as they cannot undergo the life like normal one, reducing or missing work hours and repeated taking day off. Its loss cost up to was $9000 per year (Emad & Rizal, 2013).

In Australia, study had been made by Yun, 2009 which focusing the healthcare system. The study highlighting the economy hardship for those in chronic disease which including CKD patients. One who were on multiple medication, unemployment and indigenous background were said to have major impact on financial. They jeopardize the health as the result of unbalanced economy income. Australia had health policy which the government able to support fees for the treatment. But it sometimes depending on the type of occupation or status of employment whether it is contract or permanent work in a company. The patient who does meet the criteria for the policy must use their own money

to pay for the treatment. Apart from that, those who receiving subsidies but insufficiently to encounter the long-term illness life expenditure must use their pocket money. 80% of total burden is accounted for non -communicable disease (Australia Institute of Health and Welfare, 2001).

A US study define that health resources utilization among CKD patients. It is found that CKD treatment has both direct and indirect towards patient's life cost. This is because by doing treatment, they will have to ask for medical leave or sudden absenteeism which accounts for 25% of health -linked cost of HD (Sullivan, 2007). As patient undergoes HD treatment 3 session per week, they must spend more than 10 hours of work time to completing the treatment. Thus, it will cause salary deduction every month. According to WHO, the affected populations are the lower socioeconomic status which referring to patient who does not have occupation or the salary is not high enough to pay for medical expenses.

In South Africa, the government had limited the funds for HD treatment. They able to pay half for the treatment and another half is fully paid by patient. Those who highly paid able to pay by themselves. This patient who has low income has more financial burden as they cannot afford to pay all the health facilities altogether. Sometimes patient unable to undergoes for treatment as they cannot pay it (Rafiq, 2016).

India also states that about 60% of patient had to use their own money to pay the HD treatment. It is reported that, they are having catastrophic expenses on dialysis. As a result, another 40% population had excluded themselves from getting HD treatment. Study by Mahesh (2019) reveals that although there are subsidies provided by the government there is still a lot of use from pocket money among patients. This is because, India is one of the countries that is listed as poor region but contains high amounts of

populations. The size of patient in renal also increase due to low educational level and low income to prevent this illness from spreading at India. Authors found out that prevalence of 91% patients who had financial difficulties among renal patients. They used the pocket money to pay the transportation expense. Up to 29% patient utilized up the subsidies for their household usage. From this study, it is important to take care of the health as medical expenses is costly nowadays.

But as HD is not widely used in India, they exposed the kidney transplant as an alternative treatment to medications to treat CKD. Of course, it is not easy finding the donor as far as they can as the population itself is not exposed with organs donor project. Multi studies had been conducted and it is proven that treatment for CKD imposes major financial burden on citizens. To be highlights the population in low class income (Ramachandran & Vivek, 2013).

Some countries such as Pakistan had spent most of their money on infectious disease (tuberculosis, cholera and typhoid) and spent minor amount for non-infectious disease. Employment status for CKD patient played important aspect as he or she had to pay the medical expenses. If they work at government sector, probably they will get the treatment at government hospital, thus the rate is lower than the private sector (Saqib, Shazia, Marium & Ibrahim, 2018). Some of them may applying non-government funding to continuing the treatment.

In Asian country as researchers Sripens T. et al. 2013, explained that costs on dialysis accounted for 4.1% of the 1996 healthcare budget in Japan. On the other hand, South Korea had 3.24% in 2004. Thailand, as the primer country in Asia that started the universal coverage for dialysis back in 2008. Due to that, the total amount of spending on dialysis was THB 160 million (estimated 0.2% from the total budget). Surprisingly, the

figures had increase to THB 3.9 billion as approximately 3.4% of total budget in 2012. This show that, even if the country listed as developing countries, patient must pay for HD to maintaining the economic level. Frequent hospitalization adds to financial burden.

Taiwan as explained by Hsiun (2016), reported that patient undergoes HD treatment had higher monthly productivity losses. This includes the time taken for the treatment and the cost involved for vehicles usage to the hospital. Several studies were done which the result provides clear evidence HD treatment have direct medical cost when compared to peritoneal dialysis or PD (Alessandro et al., 2017).

There were not many studies for financial burden among HD patient in Malaysia. Hence, the exact statistics of affected population cannot be trace. Fess for this treatment if funded mostly by government. The fully funded applied at government hospital or clinic. But at private or organized by NGOs, it is called as subsidies. Usually civil servants, public pensioners and their dependent will be served at private sector. Nevertheless, higher statistics showed that the usage of patient's pocket money was about 20-30% compare to funding from NGOs which is 10-13% in 2016 (MDRT, 2016). In the 24th reports on Malaysia Dialysis & Transplant Registry (2016) said that there were 37,184 patient receiving dialysis treatment.

As Malaysia had few numbers of organ donor, the alternative for renal replacement therapy was HD. The costs for treatment in Malaysia including recurrent cost which is blood test, medications, other investigation, and clinic visits. A lot of money is needed to complete pre- and post-dialysis treatment (Naren K. et al, 2018).

In summary HD greatly affects the financial of a household. Patients not only have to pay for medical fees but also non -medical fees. It is terms as healthcare costs which comprised of HD session, pharmaceutical, out-patient visit or emergency department, test

and complimentary examinations used, hospitalizations and the usage of self and medical equipment such as transportation including tolls and oils, diapers and canes. Those contribute to large sum of money which patient in low class of income cannot afford.

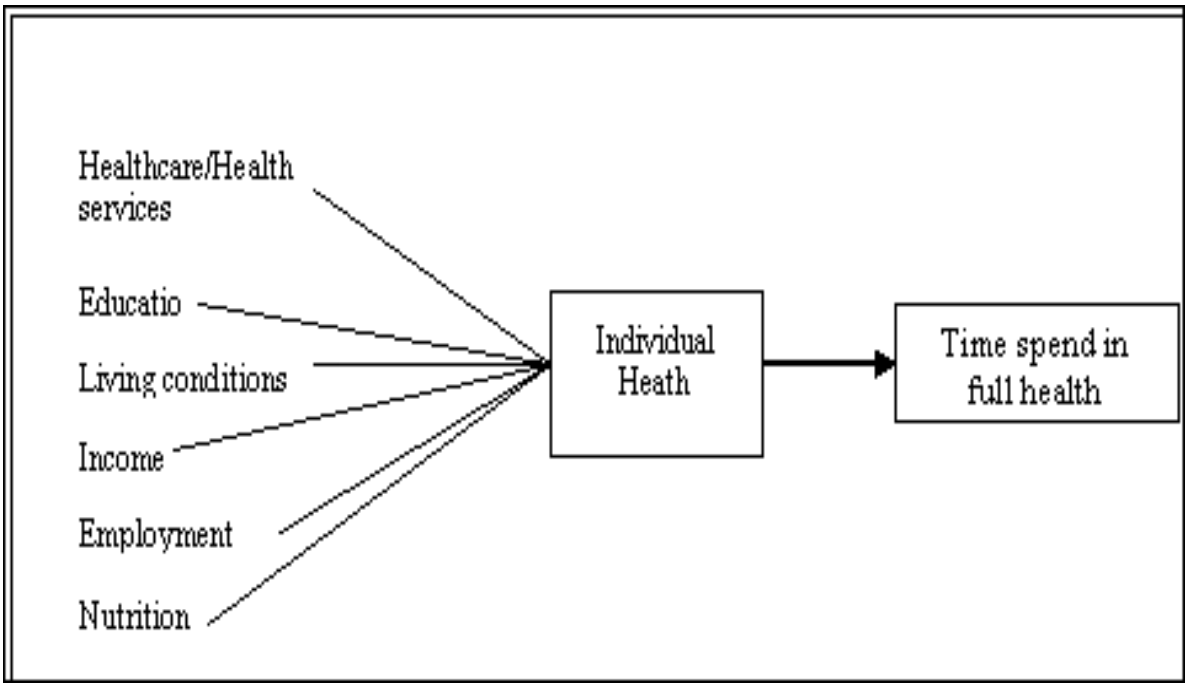

Figure 2.2 Grossman Model of Health Inputs and Output

Source: Grossman M (1972) The Demand for health: A Theoretical and Empirical Investigation.

2.3 Theoretical and conceptual framework of the study

The theoretical framework used in this study is Grossman model of health inputs and outputs. It also involving life cycle model over health. It is developed by Grossman model of the demand for health (Grossman, 2000) in continuous time (Wagstaff, 1986, Ehrlich and Chuma, 1990; Galama, 2015). The model develops a framework for associate the relationship between health, financial measure of socioeconomic status such as monthly income, type of class whether high, middle or low class of population according to their wages. Not only that, this model also provides framework for any demand for consumption, medical goods and health service and time management in health such as visiting clinic or traditional medicine. Figure 2.1 show the detail about the model.

In this framework, Grossman said that the theory economic explanation is an essential element in health-decision making. There a few elements in this theory that relates to health behavior. First, direct increase in utility or person take benefit of healthy live. Second is increased healthy time which person may invest to get benefit from the health. The investment in this context is that person having a healthy time that make them available to do activities during their leisure time. The productive aspect of health is the increase the performance on a task.

In this study, researcher able to relate that patient who's still able to do activities daily living (ADL) by themselves may maximize themselves to do the task independently. It showed that even though they were diagnosed with chronic type of kidney disease, they still able to do the daily task without any helps form other. It is highlights here that when a person able to do the job properly they may increase their monthly wage at work. Thus, financial problem could be decreased.

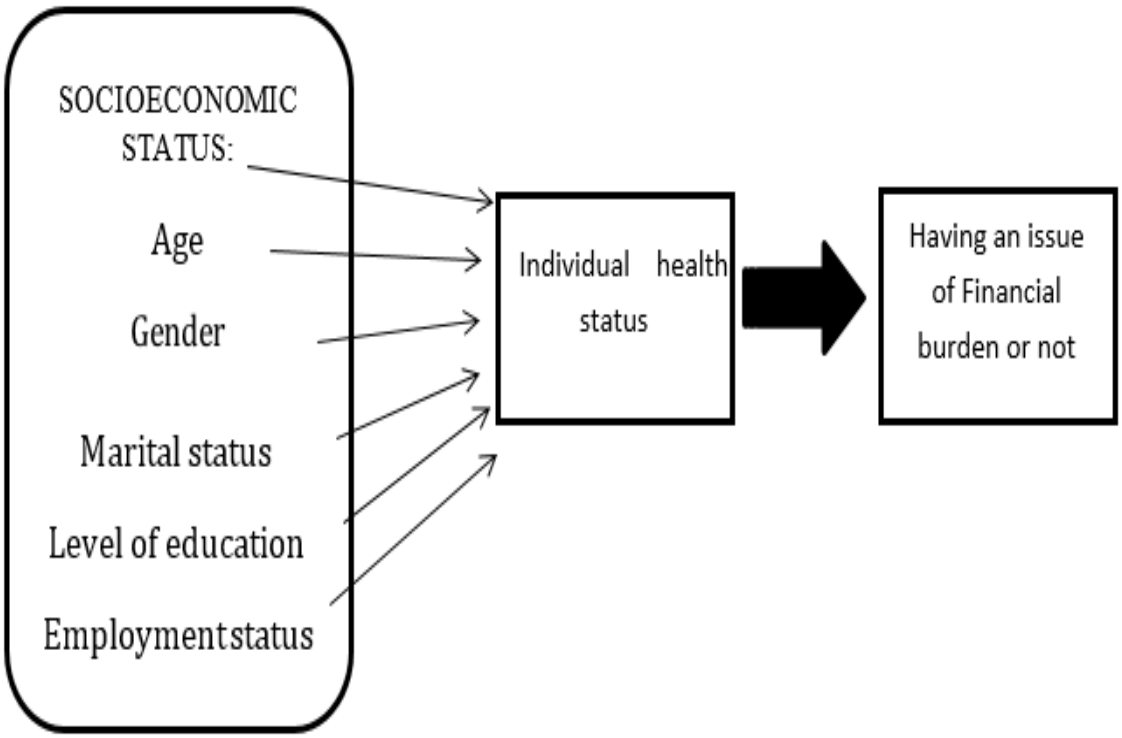

Figure 2.3 Conceptual framework adapted from Grossman 1972

In this study also showed that education is important to determine status of health in a person. Person with high education may innovate their way on making choices in life. In this study, as people gained more knowledge about their condition, they able to change their lifestyle in terms of dietary habit, exercise, and options of medication. Not only that, patient may appear more efficient in health status from better medical knowledge and more alternative sources for maintain wellbeing. Inputs in this conceptual context is the socioeconomic status which is more salary or better income classes determines better output. Output in this study is the burden on financial on HD patients. Figure 2.3 above show the conceptual framework in this study.

CHAPTER 3 RESEARCH METHODOLOGY

3.1 Introduction

In this chapter, researcher explained the purpose and rationale used to support the chosen research methodology. Determining correct and applicable research design was essential ways so that the data validated. This chapter aimed to expose the type of design used and why researcher wants to use it. Apart from that, study setting, population design, appropriate selection of participants according to criteria lists, sampling plan, sample size determination and instrumentation and collection of data which including the ethical considering right. This final section explains the proposed statistical analyses used with quantitative data.

3.2 Research Design

Research design as study by Akhtar (2016), stated the conceptual blueprint within the research. It is established for researcher's outline of correction, measurement, and analysis of data. The design used in this study was a cross sectional survey. It was conducted by using self-administered questionnaire tools. This type of design was chosen because researcher able to measure the exposure and outcome of the study participants in the same time. It was also easy to conduct as the exposure in this study are constant such as gender, age and others. Researcher aimed to study the effect of socioeconomic status on financial burdens among HD patients in Hospital USM.

3.3 Study setting and population

The study was conducted among in patients and out-patients who receiving HD treatment in medical wards (8 Selatan, 7 Selatan, 7 Utara, 1 Selatan) and in HD clinic in Hospital USM. This study was conducted at Hospital USM from October 2020 until July 2021. The duration for data collection is from January 2021 until March 2021. In this study, HD patients were selected as study participants. The method used was purposive sampling as researcher only select participants the meets the inclusion criteria. The total patients who receiving HD treatment in Hospital USM were 254. Selection of participant was divided by in and out patient. For in patient, wards involved, 8 Selatan, 7 Selatan, 7 Utara, 1 Selatan. While for outpatient, participants who have seek treatment at HD clinic in Hospital USM. This data was obtained from researcher herself as the researcher giving out the questionnaire and administered participant filling up the questions.

3.4 Sampling method

The method chosen in this study was purposive sampling. It was used in this study because researcher was interested about specific characteristic of participants which, they should be receiving HD treatment more than 3 months. This because the estimation of HD cost was more accurate compared to those who receiving HD less than 3 months in same institution.

3.5 Sampling plan

3.5.1 Inclusion criteria:

Participants selected if:

A. Participants aged 18 – 55 years old
B. Participants who received HD treatment at least 3 months
C. Understand, speak, and write in Malay and English Exclusion criteria:

Participants excluded are:

A. Have medical condition that interfere the development of study (dementia and mental problems)

3.5.2 Sample size estimation

Sampling was the process of outline in details about which measurement researcher will be use at the time. It should be designed in a way the collected data could be as representative sample of parameters of interest. It was also maximized the validity and efficiency of the research (Dragan, 2019).

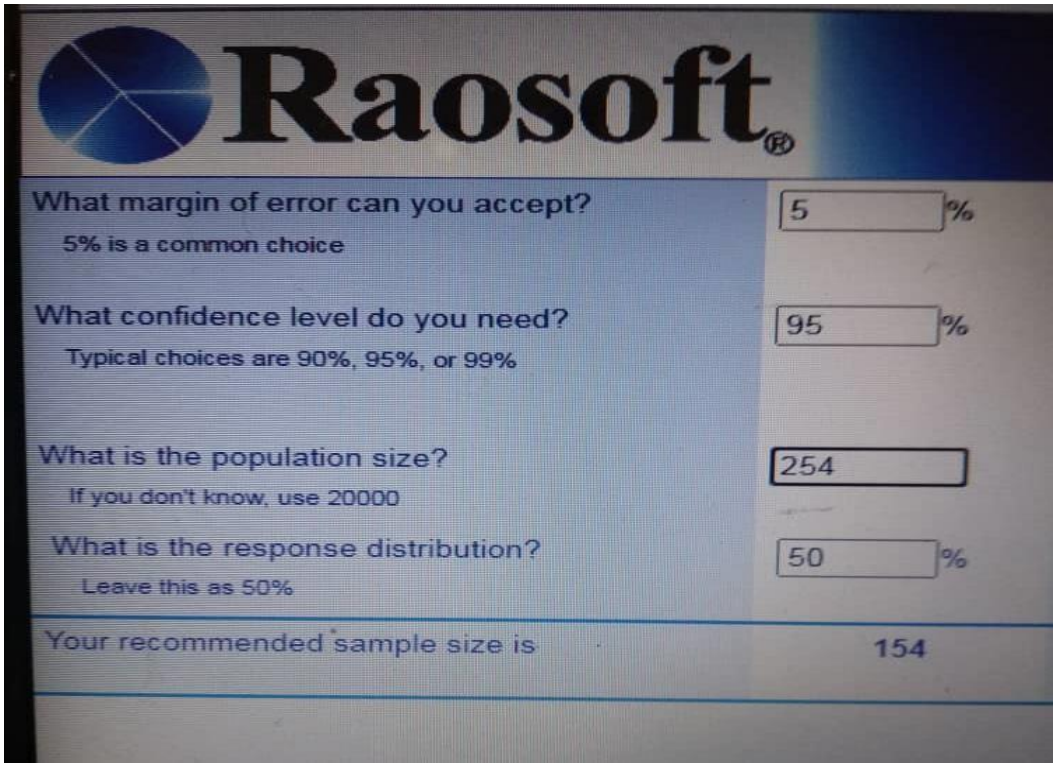

Figure 3.1: Sample size calculation by Raosoft Software

For objective 1 and 2, the sample size was calculated using Raosoft software which includes the population proportion sample size. The margin error was being set at 5% with the confidence level of 95% and the response distribution at 50%. The recommended sample size for this study was 154. With a 10% of dropout rate, the total participants required for this study as follow:

N was a number of in-patient for HD treatment at HUSM = 154 ± 10% dropout

= 154 ± 15

= 169 participants

For objective number 3, to determine the relationship of socioeconomic status and financial burden, researcher used application online which was Correlation sample size. Pearson Correlation was used in this study. the alpha was 0.05 and beta was 0.20. the r value or correlation was 0.30 according to previous study. Thus, sample size will be 85 participations.

Thus, in this study, researcher used 169 participants as the value for sample size as it was higher than 85.

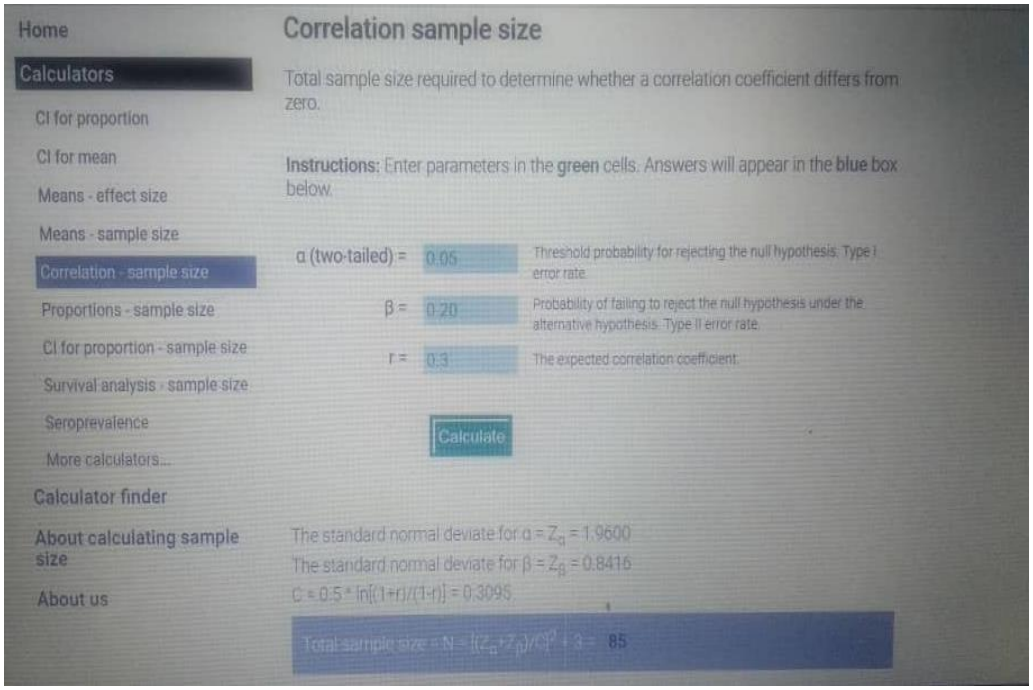

Figure 3.2: Sample size calculation by Correlation application software

3.5 Instrumentation

The instrument used in this study was on financial burden on HD patients in Hospital USM. The questionnaire was adapted from Shdaifat (2017). The permission to use this questionnaire was obtained from the author (APPENDIX A). The question was aimed to gather the information about medical and non-medical costs involved while seeking HD treatment. Demographic data also were obtained from this questionnaire. The questionnaire was a self-administered questionnaire in which patient must answer it by themselves.

3.5.1 Instrument

This questionnaire was divided into 5 sections which are Part A, Part B, Part C and Part D as follow: