Faculty of Medicine and Health Sciences

THE EXPERIENCES OF PATIENTS WITH END STAGE RENAL DISEASE LIVING ON HAEMODIALYSIS

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PENGALAMAN PESAKIT PERINGKAT AKHIR KEGAGALAN BUAH PINGGANG HIDUP DENGAN HEMODIALISIS

Lau Sie Ngo

Tesis yang dikemukakan untuk memenuhi keperluan bagi

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ABSTRACT

Haemodialysis is used as a life-sustaining therapy for patients suffering from End-stage Renal Disease (ESRD). The disease and haemodialysis (HD) treatment affect an individual physically, psychologically, emotionally, socially, financially and spiritually. This study utilized a qualitative, exploratory and descriptive method with face-to-face in-depth interview to explore the experiences of patients with ESRD living on HD treatment in Kuching, Sarawak, Malaysia. Applying purposive and snowball sampling method, a total of 28 patients from four HD centers participated in this study. Data were transcribed verbatim and analyzed using the 9-steps interpretive thematic analysis method adopted from Zabidah (2010).

Four major themes emerged: (1) Living with the paradox, (2) When life is dependent on haemodialysis, (3) Adapting into new life with haemodialysis and (4) A sense of hope in the unknown future. HD caused dependency on HD; physical limitations; restricted life; loss of freedom; employment challenges; financial difficulties; vascular access related problems; psychological distress and change of family roles and responsibilities. Patients are waiting and hoping for kidney transplants, freedom to live, restore good health, attain pre dialysis status, live healthy, and employment as mean of hopes. This study has identified gaps in the delivery of psychological care; rehabilitation in employment; spiritual, moral and emotional support in addressing the holistic nursing care toward patients on HD. Therefore, it is suggested that a more structured psychological care and financial assistance, rehabilitation in employment, spiritual, moral and emotional support be provided to patients, as well as family. Future research should explore more about the employment challenges or factor that contribute to job retention or unemployment among patients living with HD in depth.

ABSTRAK

Hemodialisis digunakan sebagai terapi memanjangkan hayat bagi pesakit yang mengalami Peringkat Akhir Kegagalan Buah Pinggang (ESRD). Penyakit dan rawatan hemodialisis(HD) memberi kesan kepada individu secara fizikal, psikologi, emosi, sosial , ekonomi dan rohani. Kajian ini menggunakan kaedah kualitatif, penerokaan dan deskriptif dengan temubual bersemuka secara mendalam untuk menghuraikan pengalaman pesakit ESRD yang hidup dengan rawatan hemodialisis di Kuching, Sarawak, Malaysia. Melalui persampelan bertujuan dan pendorong , sebanyak 28 peserta dari empat pusat HD secara sukarela mengambil bahagian dalam kajian ini. Data telah ditranskrip verbatim dan dianalisis dengan menggunakan 9-langkah tafsiran kaedah analisis tematik yang berasal daripada Zabidah (2010).

Empat tema utama ditemui : (1) Hidup dengan paradoks, (2) Apabila kehidupan adalah bergantung kepada hemodialisis, (3) Menyesuaikan diri ke dalam kehidupan baru dengan hemodialisis, dan (4) perasaan harapan pada masa depan yang tidak diketahui. HD mengakibatkan pergantungan kepada HD, batasan fisikal, kehidupan terhad, cabaran pekerjaan, masalah kewangan, masalah berkatian dengan akses vaskular, kesusahan psikologi dan perubahan peranan dan tanggungjawab keluarga. Pesakit menunggu dan mengharap pemindahan buah pinggang, kebebasan untuk hidup, memulihkan kesihatan baik, mencapai status pra dialisis, dan pekerjaan. Kajian ini telah mengenalpasti jurang dalam penyampaian penjagaan psikologi, pemulihan dalam pekerjaan, sokongan rohani, moral dan emosi dalam menangani penjagaan kejururawatan holistik kepada pesakit HD.

Oleh itu, adalah dicadangkan bahawa penjagaan psikologi dan bantuan kewangan yang lebih tersusun, pemulihan dalam pekerjaan, sokongan rohani; moral dan emosi perlu disediakan kepada pesakit serta keluarga. Kajian masa hadapan harus meneroka lebih lanjut mengenai cabaran pekerjaan atau faktor menyumbang kepada pengekalan pekerjaan atau pengangguran di kalangan pesakit yang hidup dengan HD.

DECLARATION

No portion of the work referred to in this thesis has been submitted in support of an application for another degree of qualification of this or any other university or institution of higher learning.

Signature:

Name:

Date:

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LIST OF ABBREVIATIONS

ANZDATA	Australian and New Zealand Dialysis and Transplant Registry
AVF	Arteriovenous fistula
CKD	Chronic Kidney Disease
CVC	Central Venous Catheter
ESRD	End Stage Renal Disease
QoL	Quality of life
HD	Haemodialysis
IJC	Intra-jugular Catheter
MDTR	Malaysian Dialysis and Transplant Registry
MOH	Ministry of Health
NGO	Non-Government Organization.
PD	Peritoneal Dialysis
SGH	Sarawak General Hospital
SOCSO	Social Society Organization
UNIMAS	Universiti Malaysia Sarawak
USRDS	United States Renal Data System

KEY TO TRANSCRIPTIONS

The following abbreviations and conventions have been used in the presentation of research findings:

Keys or symbols	Meaning(s)
"Italics"	Represent the interview data from the study participants. The Original text was in Malay, Mandarin and was translated by researcher. However, where it is not possible to translate adequately, the spoken Malay language is retained.
Names	Pseudonyms are used for the study participants to maintain confidentiality throughout the study.
...//..	This symbol in the excerpts indicates material deleted from the interview excerpts.
…	This symbol represents a pause during interview process, and/or unrelated words, phrases or sentence in the excerpts by the participants.
[ ]	This symbol denotes researcher's alteration for clarity.

(Zabidah, 2010)

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CHAPTER 1

INTRODUCTION

1.0 Introduction

Malaysia Dialysis and Transplant Registry (MDTR, 2012) stated that there were around 25,000 people suffering from end-stage renal disease (ESRD) and were on haemodialysis (HD), or peritoneal dialysis (PD) or a kidney transplant in order to stay alive. HD is the most common method used as a life-sustaining therapy for patients with ESRD (MDTR, 2012). Studies reported that HD affects all aspects of ESRD patients' lives as well as those people around them (Calvey & Mee, 2011; Clearly & Drennan, 2005). Due to the rapid increase of ESRD patients, the provision of physical care and psychological support by the health care professionals may be lacking. This study is aim to gain a better understanding on the experiences of patients with ESRD on HD treatment in order to improve and provide holistic care to them.

This chapter begins with introducing the motivating factors of doing this study, reflecting and explaining how my professional involvement with ESRD patients who were on HD treatment had triggered me to study further on this issue. This chapter also includes the background of the study, statement of the problem, research questions, research objectives, and the significance of this study. Key terms are operational defined. The chapter concludes with an organization of the thesis.

1.1 The motivating factors of this study

This study derived from a few short, informal conversations with ESRD patients who were receiving HD treatments in my working place. The patients revealed that they faced many difficulties, challenges and problems in their lives when going through HD treatment.

The first informal conversation was with a female patient, Viviana. She experienced extreme tiredness and weakness after developing hypotension during HD treatment. Viviana said the tiredness had caused her difficulties in climbing stairs, walking, bathing, and even performing her house works. She felt sad, useless and hopeless as she was unable to fulfill her role as a housewife.

The second informal conversation was with a male patient, Chee. Similarly, Chee also said that he developed adverse events of HD such as hypotension and giddiness. On the way back after HD, he fell down from his motorcycle and lost consciousness. He was been sent to the emergency department of a hospital by a passer-by.

The third incident was about Ling, a male patient referred by other HD center to HD center at Sarawak General Hospital (SGH) because of anemia. After communicating with him, I found that his HD treatment and injection erythropoietin was sponsor by the Social Society Organization (SOCSO). As the dose of injection erythropoietin that he required was more than the entitlement that he can received, he needed to pay for the extra cost of erythropoietin injection. However, due to his financial constraint, he was unable to do so. As such, he only received the

dose according to his funded amount that was lower than the prescribed dose. Not able to receive the prescribed dose of erythropoietin injection was the cause of Ling's anaemia. Ling looked very lethargic, worried and concerned about his health. Viviana, Chee and Ling' stories were just among the many experiences on lifelong HD that patients had shared with me. Reflecting on the above HD patients' stories, I began to pick out those problematic situations, thought about the problems in a new way, and was eager to explore more. Numerous questions arose in my mind regarding patients' experiences while living with HD. I wondered how ESRD patients perceived their HD treatments. What were their thoughts after going through HD treatment? How did they face those difficulties, challenges and problems that they might face? How did they cope with their experiences? Those encounters had triggered me to reflect on my past professional experiences as a renal dialysis nurse in the HD unit.

During these fifteen years working in three different public HD units in Sarawak as a dialysis nurse, my major focus was on patients with ESRD. Patients with ESRD are unable to produce urine to eliminate the accumulated toxins in their bodies and as a result, suffered fluid and electrolyte imbalance. It is crucial for the toxins, electrolytes and fluids to be removed on a regular basis for patients to survive. HD serves as a life-saving process for patients in end stage, or chronic, or acute kidney injury as it imitates the kidney's primary functions. My major roles included operating the HD machine, providing care and cannulation of arterio-venous fistula (AVF), hooking up the patient to the HD machine, monitoring the patient during the HD process to determine adverse events of HD, management of adverse effects resulting from HD, and terminating HD sessions. I also performed other activities, such as giving health advice and education, giving medication, transfusing blood and blood product during HD, performed

dressing and care of the central venous catheter (CVC) when necessary.

Besides that, I have encountered and nursed many patients who experienced adverse effects of HD, which included hypotension, nausea, vomiting, muscle cramps, giddiness, cardiac arrhythmias, blurred vision, restlessness, fever, seizures, or even worse, coma. Hagren, Pettersen, Severinsson, Lutzen, and Clyne (2005) in Sweden; Lee, Lin, Chaboyer, Chiang and Hung (2007) in Taiwan, and Kaba, Bellou, Lordanou, Andrea, Kyritsi, Gerogianni, Zetta and Swigart (2007) in Greece also reported ESRD patients experiencing adverse effects of HD. I often had patients complain of fatigue, tiredness, insomnia, and unable to perform daily living activities after initiation of HD treatment. These experiences were also been reported in studies conducted by Lee *et al.* (2007) and Kaba *et al*. (2007).

From the anecdotal report, my experiences and my observations, I was aware that many patients were not compliant to their medications. Despite the advices and health educations given by the nephrology team, patients did not take their medications according to the prescription. Among the reasons given were either they forgot to take their medication, no more medication available, or they did not bring medication together when they dined outside.

Besides that, the majority of patients were not compliant to dietary restriction. The patients consumed a lot of food during HD treatment. The amount of fluid that they took was always more than the recommended amount, which presented in weight gain, 3 to 4 kilograms in between HD sessions. While I re-enforced on dietary and fluid control, patients always told me about their difficulties in fluid control. They normally complained that the weather was too hot

and they were very thirsty. Due to increased fluid consumption, some patients developed difficulty in breathing, unable to lie flat and unable to sleep, which caused them to visit to the emergency department. Consequently, some patients developed acute pulmonary oedema and required admission to intensive care unit of a hospital and were intubate. Some patients survived after daily HD treatment and with the support of advanced technology and other medical devices such as ventilator. Unfortunately, some patients died.

Other than that, I also realized that some patients shortened the duration of HD treatment, especially those self-care patients. They terminated the HD sessions before they completed the 4-hour dialysis. Some patients who depended on nurses to perform HD procedure would request nurses to help them to terminate HD early. If nurses did not fulfill their requests, they would get angry and sometimes even scolded the nurses. Some patients intended to skip one session of HD treatment in a week, whereas some patients did not turn up for the HD treatment as scheduled, especially during festival time. Some patients would give reasons for not turning up for HD, but some patients would not. In fact, some patients would be angry when the nurses asked for an explanation. The issue of non-compliance had created conflict among patients and nurses. The issue of skipping HD treatment was also been observed in a study done by Laupacis, Keown, Pus, Krueger, Ferguson, Wong and Murihead (1996).

The above incidents and situations had made me realized that nurses needed to know more about the HD patients' life experiences because a better understanding of these experiences would ensure good quality patient care. I also realized that there was a great need to render holistic care to patients with HD treatment to improve their quality of life. In an effort to improve my

understanding on this important issue, I started to search for more information about the experiences of ESRD patients living with HD from the journals and from the internet.

From my literature search, I found very few published quantitative research and no qualitative research done regarding the experiences of patients living with HD in Malaysia. However, there were some research studies conducted in foreign countries which examined kidney failure patients' experiences, adaptation, stressors, coping mechanisms and quality of life in the quantitative paradigm, and also some research conducted in qualitative paradigms in order to understand the patients' experiences with HD. However, I was concerned for the generalizability of research findings from foreign countries to Malaysia, particularly in Sarawak. This is due to the differences in culture, physical infrastructure, health care system and local support system that may influence how the patient thinks, feels and behaves, hence, could have influenced these ESRD patients' experiences with HD. As a renal dialysis nurse, I was deeply concerned with the perception, feeling and coping strategies of ESRD patients' with HD treatment. Thus, this concern had prompted me to conduct the present study.

1.2 Background of the study

Haemodialysis (HD) is the most common method of treatment used worldwide to treat ESRD (United States Renal Data System, USRDS, 2002), as well as in Malaysia (MDTR, 2012) due to the limited number of donor available for kidney transplantation.

The HD services in Malaysia have progressively developed since the early 1970s. Currently, there are around 580 HD facilities in Malaysia (MDTR, 2012). This rapid growth of HD facilities are made possible through the collaboration of three key stakeholders of health in Malaysia, such as the Ministry of Health (MOH) and other government agencies, private healthcare providers and the Non-Government Organizations (NGOs). According to MDTR (2012), out of the 25,688 ESRD patients in Malaysia, 92% are receiving HD treatment with 31 % receiving HD treatment provided by the MOH hospitals, 27 % by NGO HD centers and about 42 % by the private sectors (Lim, Ong & Goh, 2012).

In Sarawak, HD treatment services began in 1981 that was been provided only by the Health Ministry (Sarawak State Health Department, 2012). The Statistics from SGH in 2011 revealed that out of 1,834 patients diagnosed with ESRD in Sarawak, 1610 (87.8 %) patients were receiving HD treatment which was provided by public, NGO and private HD centers (Sarawak General Hospital, 2012, unpublished data).

HD therapy is conventionally performs three times per week, for about 3 to 4 hours for each session. Individual patients with specific problems may require more frequent dialysis. This routine HD is usually conducted in an HD outpatient facility, or in a hospital, less commonly done at home, so patients are required to travel to a designated HD center, either been managed by MOH, NGO or private sector. They had to stay in HD center for 4 to 5 hours every alternate day to receive the HD treatment for the rest of their lives. The patients with ESRD are required to follow a complicated treatment protocol that includes frequent and lifelong HD sessions, strict dietary and fluid restrictions, and a complex medication regimen (Thomas, 2004).

1.3 Problem Statement

The number of ESRD patients in the world is been estimated to be around 2,786,000 at the end of year 2011 (Fresenius Medical Care, 2012). In Malaysia, the 19th Report of MDTR in 2012 stated that the numbers of ESRD patients had almost tripled in the past 10 years from 9,107 in year 2002 to 25,688 in year 2011, with an addition of 5000 new ESRD patients every year (Lim, Ong & Goh, 2012). ESRD patients experienced an irreversible loss of the kidneys' ability to excrete waste products and to regulate electrolyte and water balance. This condition is also associated with cardiovascular dysfunction, malnutrition, anemia, muscle wasting, muscle weakness, glucose intolerance, neuropathy, reduced bone density and reduced psychosocial functioning as well as reduced quality of life (Lii, Tsay & Wang, 2007).

Patients with ESRD faced many challenges and changes in their lives with the initiation of HD treatment. They are been compounded with the additional burden of chronic complications of the disease, and complications of HD treatments leading to increased morbidity and premature mortality (Himmelfarb, 2005). Thus, they had to deal with the stress of chronic illness as well as HD treatments, which lead to non-adherence to the HD regimens, medication and dietary control. The patients who failed to adhere to HD regimens may result in short-term and long-term consequences for health and survival (Denhaerynck, Manhaeve, Dobbels, Garzoni, Nolte, & De Geest, 2007). In the short-term, non-adherence to treatment regimens may increase the likelihood of emergency and hospital admissions. The development of additional co-morbidities, like cardiovascular disease, mineral bone disease, and mortality are potential long-term consequences (Denhaerynck *et al.*, 2007). The issue of non-adherence to the HD regimens,

medication and dietary control among ESRD patients posed a huge challenge to nurses and other health care professional in providing health care.

My earlier reflection on HD patients' experiences in the HD centers was base on my own perception and past experiences. My perspective of problems, challenging and difficulties encountered by the HD patients included weight changes, skipped or shortened HD treatments, noncompliance with medication, fluid and dietary restriction which might reflect patients' knowledge and adherence to the rules of surviving ESRD and HD treatment. However, the patient' perspective on their real experiences might be different from my perspective. Rittman, Northsea, Hausauer, Green and Swanson (1993) recommended that nurses needed to understand the experiences of living with ESRD from the patient's perspective in order to effectively assist them to live with this chronic illness. Scaife (2006) also recommended early identification of the patient's needs so as effective coping skills and strategies could be included in the care plan of all HD patients. Kaba *et al*. (2007) also supported that nurses must make efforts to understand the driving force behind patients' actions. Thus, the inform-based understanding on experience of HD patients is necessary for nurses in order to assist the patients to adjust to the illness and treatment effectively, as well as to overcome stress, anxiety, or depression. Quantitative research, used primarily on Scandinavian or European or American subjects, has documented the impact of ESRD and HD on physical, functional status, independence, general well-being, personal relationships, social functioning, and quality of life (Suet-Ching, 2001).

The number of ESRD patients on HD in Malaysia is on the increase every year. Yet, there is little published information regarding local Malaysian patients' experience on their disease and

HD treatment, as well as their coping strategies. Although findings from foreign studies are available, these may not be appropriate to be apply in Malaysian setting, thus, it is imperative to conduct a local study. I conducted this present study to explore the experiences of the patients with ESRD who are undergoing regular HD treatment in Kuching, Sarawak, Malaysia.

1.4 Research questions

The research questions posed for this study in the light of the issues and problems highlighted above are as follows:

a) What is the experience of patients with ESRD living with regular HD treatment?
b) What is the impact of HD treatment on ESRD patients and their family?
c) What are the coping mechanisms used by ESRD patients with HD in Malaysia?

1.5 Research objectives

1.5.1 General objective

The general objective of this qualitative study was to explore the experiences of patients with ESRD living with routine HD treatments in Kuching in order to have a deeper understanding of the life of Malaysian ESRD patients.

1.5.2 Specific Objectives

The specific objectives are:

a) To explore the experience of patients with ESRD living with regular HD treatment

b) To explore the impact of the HD treatment on ESRD patients and their family

c) To explore the coping mechanisms used by ESRD patients with HD

1.6 Significance of the study

The finding of this study would illuminate the experiences, thoughts and concerns of patients with ESRD living with HD in Kuching, Sarawak. It would add to the existing literature on ESRD in providing evidence-based information about the effects of HD treatment on patients and their families; physically, psychologically, socially, emotionally, and spiritually. It would also provide evidences to ESRD patients on long term HD how to cope with these adverse effects in order to achieve an acceptable level of quality of life. The findings of this study would also be used by health care providers to deliver more effective and efficient services to these patients. Furthermore, the study finding could also be used as a basis for future research.

1.7 Operational definitions of terms

There are several terms used in this study that are operationally defined.

(a) Experience

Experience is been defined as a particular instance of personally encountering or undergoing something (Dictionary.com, 2014). The experience in this study was been defined as how the patients with ESRD on HD treatment felt when encountered with the physical, psychological, social, financial, and spiritual or their disease and treatment. A set of question guide was been used in the interview to obtain the data.

(b) End Stage Renal Disease patients

End-stage renal disease (ESRD) refers to Stage 5 of Chronic Kidney Disease (CKD) that occurs at the last stage of progressive impairment of kidney function (National Kidney Foundation, 2002). This stage 5 represents the end of kidney function. The kidneys are working at less than 10 to 15% of normal function. The kidneys lose the ability to remove waste product and excess fluid from the blood, fail to produce hormones to regulate blood pressure and fail to stimulate red blood cell production and active vitamin D production. Patients with ESRD in this study referred to those patients who were diagnose and were on HD treatment at the time of data collection.

1.8 Organization of the thesis

This chapter explains the impetus for this research. It also provides an overview and background of the study, statement of the problem, research questions and objectives and its significance. It also includes the definition of terms.

Chapter Two provides a detailed literature review of research studies done on the experiences of ESRD patients living with HD treatments and the impacts of HD on the patients and their family, and the coping strategies that patients used for these impacts.

Chapter Three discusses the research design, research setting, the study participants, sampling method and sample size. It also provides detailed information on the data collection, data analysis, and justifications for the methodology used in the study.

Chapter Four discusses the findings with the focus to answer the research questions and research objectives. Detailed description of the patients' experiences living with HD is been presented in themes and sub-themes.

Chapter Five provides detailed discussion of the study findings.

Finally, the last chapter presents the implication of the findings and recommendations for nursing practices, patient educators, policy makers and future research. This chapter ends with the limitation of the study and the conclusions of this study.

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

This review of the literatures in this chapter focuses on the experiences of patients with ESRD on HD treatment includes the necessity, dependency, physical effects, socioeconomic effects, psychological and emotional effects of haemodialysis. This chapter also discusses the effects of haemodialysis towards family, and the various adapting and coping strategies used by the patients to manage the effects of HD treatments. Finally, a brief summary concludes this chapter.

2.1 The necessity for haemodialysis treatment

My literature searches found that HD treatment was necessary for patients with ESRD in order to sustain their life (National Kidney Foundation, 2002). The HD treatment helps to remove biological waste products and excess water from the blood, and to regulate certain electrolytes in the patients' body (Himmelfarb, 2005). Before the initiation of HD, all patients are required to undergone AVF creation, which is usually create on the non-dominant arm to supply the necessary blood flow for the HD process. However, if HD treatment needs to be started before the AVF is matured, the patients need to undergo insertion of (central venous catheter) CVC at either side of the neck as a temporary access for the HD process (National Kidney Foundation, 2002).

Before starting HD, two AVF needles need to insert into the AVF that would then connect to a bloodline on the HD to allow a large amount of blood to be withdrawn from one lumen, to enter the dialysis circuit, and to return to the patient's body via the other lumen. The blood would flow through the dialyzer (artificial kidney) where HD takes place and then the "cleansed" blood is return to the patients' body (National Kidney Foundation, 2002).

Besides that, nutritional management is an important part of the treatment plan for ESRD patients. Patients must keep their potassium levels between 3.0 to 6.0mmol/l (Moosa, Naicker, Naiker, Pascoe, & van Rensberg, 2006) because excessive dietary potassium intake may lead to hyperkalemia and fatal cardiac rhythm abnormalities (Christensien & Ehlers, 2002). Patients must also keep their phosphate levels between 1.4 to 2.0 mmol/l (Moosa, Naicker, Naiker, Pascoe, & van Rensberg, 2006) as phosphate retention can lead to mineral bone disease and may contribute to cardiovascular disease (Christensien & Ehlers, 2002). Excessive fluid can result in fluid build-up around the lungs, causing high blood pressure and shortness of breath (Moosa, Naicker, Naiker, Pascoe & van Rensberg, 2006). Therefore, ESRD patients are limited to approximately 700-1000 ml of fluid per day, and must keep their body weight gains in between HD session from 0.5 to 1 kilogram per day (Moosa, Naicker, Naiker, Pascoe, & van Rensberg, 2006). Prolonged fluid overload is associated with pulmonary oedema, hypertension, congestive heart failure, and shortened patient survival (Wolcott, Maida, Ciamond, & Nissenson, 1986). Thus, an ESRD patient's diet is restricted in fluid, potassium, sodium, phosphorus and protein.

ESRD patients with anemia can be treated with injections of erythropoietin (Banasik & Copstead, 2001). Patients would need iron supplements given orally or in intravenous preparation. ESRD

patients who develope hypocalcemia and hyperphosphatemia would be treated with calcium and vitamin D supplements. ESRD patients also need calcium, folic acid, iron and other water-soluble vitamins because vitamins and minerals may be lacking in patients' diet due to the need to avoid so many foods. At the same time, HD also removes some vitamins from patients' body (Banasik & Copstead, 2001). Therefore, ESRD patients who receive HD need to strictly comply with medications, diet control and fluid restriction in order to optimize their health and well-being (Finnegan-John & Thomas, 2013).

2.2 Life is dependent on haemodialysis

ESRD is a life threatening chronic illness. The ESRD patients were been reported to be dependent on HD treatment to sustain and prolong their life (Hagren, Petterson, Severinsson, Lutzen & Clyne, 2001). Hagren *et al*. (2001) stated that patients in Sweden understand their lives are dependent on HD. They viewed the HD unit as a place where their lives were depending on, and a familiar place that the HD activity took place. Besides that, they admitted of been dependent on family members, including children in activities daily living, and dependent on medical and nursing staff to provide care (Hagren *et al.,* 2001). Sadala and Lorencon (2006) also have similar findings. They found HD patients in Brazil were totally dependent on nurses. In Sadala and Lorencon's study (2006), 15 patients were been interviewed. Participants´ descriptions were been analyzed using Merleau Ponty's Existential phenomenological procedures. The patients expressed feeling of being in the others' hand, and depended on the health care professionals' efficiency and skills to provide care such as AVF cannulation. They appreciated and acknowledged the nurses' skills regarding the procedures.

Other than that, ESRD patients also admitted that they were totally dependent on an HD machine to provide HD treatments. They were very aware that without an HD machine they would not survive (Hagren *et al.*, 2001). Sadala and Lorencos (2006) found life of patients on HD in Brazil revolved around the HD machine. The machine was been perceived as the only way for survival. The efficacy of the HD was a source for anxiety for the patients.

Numerous studies reported that when life is depending on HD treatment and HD machine, patients with ESRD experience its positive and negative effects in physical, psychological, emotional, financial and social aspects of their lives (Hagren *et al*., 2005; Al-Arabi, 2006; Kaba *et al*., 2007). The following sections discuss these effects.

2.3 Physical effects of haemodialysis

After the initiation of HD treatment, ESRD patients experience positive and negative physical effects. ESRD patients would benefit from the HD treatment because their uremic symptom reduces and they would feel much better. Sadala and Lorencon (2006) reported that their patients experienced improvement of renal failure symptoms, felt progressively better and had some improvement in quality of life as they could perform normal functions like walking and doing house chores. Some of them mentioned that HD had brought them lives and hopes of getting well soon. They appreciated the benefits brought by HD. These positive physical effects were been identified by Ginieri-Coccossis, Theofilou, Synodinou, Thomas, and Soldatos (2008). Nevertheless, patients often reported dialysis adverse events, either during HD or after HD treatments such as fatigue, hypotension, giddiness, vomiting, muscle cramp, and insomnia

(Polaschek, 2003; Caplin, Kumar, & Davenport, 2011). Polaschek (2003) done a qualitative study on six Caucasian men in New Zealand and found that they suffered from adverse events of HD treatment such as vomiting, headache, leg cramps, lack of physical strength or fatigue, difficulties with extreme tiredness after HD treatments. Caplin, Kumar and Davenport (2011) in London, United Kingdom reported similar findings in 550 HD outpatients. In their study, Caplin et al. (2011) found the commonest dialysis-associated symptoms were fatigue (82%), intra-dialytic hypotension (76%), muscle cramps (74%), and dizziness (63%), followed by headache (54%), pruritus (52%) and backache (51%).

Among all these negative physical effects, fatigue was the major physical effect experienced by patient on HD (Hargen *et al.*, 2005; Al-Arabi, 2006; Kaba *et al.*, 2007; Tong *et al*., 2009; Yodchai, Dunning., Hutchinson, Oumtanee, & Savage, 2011). The prevalence of fatigue was as high as 71% in patients on long-term HD therapy (Murtagh, Addington-Hall & Higginson, 2007). In an exploratory phenomenological study done by Lee *et al.* (2007), 14 adult renal failure patients who received regular HD in Taiwan shared their fatigue experiences. Lee *et al.* (2007) found that the physical discomfort caused by fatigue was been induced by the long-term HD and uremia itself, whereas habitual fatigue happened immediately after the regular HD session. Lee *et al.* (2007) also found that this common and complex phenomenon decreases the patients' physical functioning. In a national, cross-sectional quantitative survey conducted by Polner *et al*. (2011) in Hungary, a total of 4,321 chronic HD patients in 56 dialysis centers also expressed their decline in physical functioning due to fatigue which significantly limited them in their daily living activities. Almost half of them reported that they needed help because they were unable to perform their basic daily living activities independently such as bathing, getting dressed, and

walking most of the time. The higher levels of fatigue associated with physical inability and decline in physical functioning was been identified in other quantitative studies (McCann & Boore, 2000; Heiwe, Clyne, & Dalhgren, 2003; Kastrouni, Sarantopoulou, Aperis & Alivanis, 2010).

Besides fatigue, Calls, Rodríguez Calero, Hernández Sánchez, Gutiérrez Navarro, Juan Amer, Tura and Torrijos (2009) reported that pain was very common and highly prevalent among HD patients in their descriptive and cross-sectional study. Twenty- seven patients on HD participated in this study. Patients felt pain every day, particularly during the day of dialysis and for a prolonged period of time. Patients informed that pain had limited their abilities to perform certain daily living activities, like walking and their general activity. Calls *et al.* (2009) stated the causes of pain were ischaemic pain (37%), cramps, headaches and pain caused by vascular access, and musculoskeletal pain were prevalent (approximately 30% each) during haemodialysis. Musculoskeletal pain accounted for about 77% even between the HD sessions. Other studies (Davison, 2003; Davison & Jhangri, 2005; Murtagh, Addington-Hall, & Higginson, 2007) revealed that the pain was a common generalized symptom that affected the daily livings of HD patients.

Other than that, Aitken, McLellan, Glen, Serpell, Mick, Mactier and Clancy (2013) found patients on HD in Scotland shortened their HD sessions or missed HD sessions due to inability to tolerate dialysis via AVF, with pain cited as the primary reason. Aitken *et al.* (2013) utilized a pain score questionnaire to collected data from 449 patients dialyzing via AVF. They found 1% (5) patients report occasionally missed dialysis sessions and 11.3% (53) patients shortened the

dialysis session due to pain. Bay, Van Cleef and Owens (1998) reported similar findings. Figueiredo, Viegas, Monteiro and Poli-de-Figueiredo (2008) stated that repeated AVF punctures lead to a considerable degree of pain and stress, due to the size and length of the bevel of fistula needles.

Polaschek (2003) reported sleep disturbances among HD patients. In another study done in Taiwan by Lee *et al*. (2007) found patients experienced sleep difficulties include insomnia, difficulty falling asleep and frequent waking from sleep as a result of the disease, HD treatment, and medications.

Patients receiving HD through CVC in Brazil reported that they experienced many other problems related to renal vascular access in a prospective-segment study conducted by de Andrade and Ferreira (2007). Among 64 patients who participated in this study, catheter implantation problems occurred in 21 patients (14.5%), eight (5.5%) had difficulty to tap a vein, four (2.8%) with intense bleeding during insertion, and four (2.8%) had hematomas. The most frequent complication in 18 patients (28.1%) was fever, followed by catheter insertion pain in 16 (25%) and dirty catheter dressing in 11 (17.2%), whereas 30 (49%) out of 64 patients develop catheter-related bloodstream infection. According to Australian and New Zealand Dialysis and Transplant Registry (ANZDATA, 2011), catheter-related blood stream infection was a major vascular access complication in patients on HD with CVC. CVC is the main cause of between 48% and 73% of all bacteremias during HD treatment that contributed to hospitalization, and remains as one of the leading causes of death in the HD population in New South Wales. HD patients experienced many complications related to renal vascular access were also identified in various

studies (Allon & Robbin, 2002; Barracca, Pili, Spina, Murgia, Menneas, & Manca, 2002; Martin-McDonald, 2004; Hagren *et al*. 2005; Tanyi & Werner, 2008). Besides that, catheter-related bacteremia was associated with serious morbidity and mortality (National Kidney Foundation, 2005; Krzanowski, Janda, Chowaniec, & Sułowicz, 2011). While experiencing the physiological effects, patients with ESRD also encountered socioeconomic effects of HD.

2.4 Socioeconomic effects of haemodialysis

ESRD and HD treatment also have negative effects on patients' social economic status. The patients' ability to perform normal daily activities, such as working, socializing and travelling are affected while on regular HD treatment. They faced restriction and limitation in their life, loss of freedom, lack of employment, and financial difficulties and constraints. After initiating HD, ESRD patients' life is restricted. Wadd, King, Bennett and Grant (2011) did a systematic review in Australia. They found that all patients on HD highlighted their lives were restricted while they need to travel to HD center every alternate day and struggling with time-consuming HD treatment.

Other than that, Mok and Tam (2001) found fluid restriction was the biggest problem and difficulty among 50 Chinese ESRD patients on HD in Hong Kong that led to social restriction. The restrictions affected daily routines and family dynamics, ability to travel far from an HD unit, exercising and performing their past social activities.

Patients also experience a lack of freedom. Many studies were done to determine contributing

factors of loss of freedom (Lindqvist, Carlsson, & Sjoden, 2000; Hagren *et al*, 2001; Polaschek, 2003; Herlin & Wann-Hansson, 2010). In an exploratory descriptive study conducted by Lindqvist, Carlsson, and Sjoden (2000), 86 HD patients expressed lack of freedom resulted from their HD treatments. They were unable to go away on short notice, and everything had to be carefully plan. Hagren *et al.* (2001) in Sweden found patient's freedom were been restricted, as they needed to be dependent on the HD machine. Their usual routines were been replaced by the time spent on the HD unit. They informed this loss of freedom altered marital, family and social relationships. Besides that, Polaschek (2003) reported that the restricted HD regimens decreased frequency, choice and quality of family holidays. In another study, Herlin and Wann-Hansson (2010) revealed nine HD patients in Sweden experienced total lack of freedom, as they had to adhere to the treatment times. They had neither vacation nor feeling of being free, as they had to follow the treatment times. Another study done by Finnegan-John and Thomas (2013) in London identified all this combination of diet and fluid restriction, travel regularly to HD center, lengthy HD treatment time impacted patients' freedom, and reduced time for leisure, family and social activities further affected patient' quality of life.

ERSD and HD treatment also affected employment of the patients. According to Jansen, Rijkena, Heijmansa, and Boeschotenby (2010), labour participation among 166 Dutch ESRD patients on HD appeared to be low. Although 62 patients were of working age, ranging from 18 to 64 years, only fifteen (24%) of the patient performed paid work for at least 12 hours per week, which was much lower than the general working Dutch population in 2006. Besides that, in the Dialysis Outcomes and Practice Patterns Study carried out among 4,123 HD patients of working age reported that only 21% of dialysis patients in the United State of America, 30% in Europe, and 55%

in Japan were employed (Dickinson, Bodfish, Pisoni, Akizawa, Locatelli, & Akiba, 2000). HD patients who had less work participation were also been reported in other studies (Van Manen, Korevaar, Dekker, Reuselaars, Boescholen, & Krediet, 2001; Waddell & Burton, 2006; Theofilou, Synodinoua, & Panagiotakic, 2013).

Numerous studies had examined the factors contributing to lack of employment among ESRD on HD. Muehrer, Schatell, Witten, Gangnon, Becker and Michael Hofmann (2011) did a study in America and found that ESRD patients who had employee group health plan or other medical insurance were more likely to maintain their level of employment (68% and 65%, respectively). Some ESRD patients were unemployed due to impaired physical and psychosocial functioning (van Manen *et al.*, 2001). Fatigue and weaknesses restricted patients' abilities to work were also reported (Tong *et al*., 2009). Some patients were forced to retire because they were unable to work overtime (Caress, Luker, & Owens, 2001; Smith & Soliday 2001; Al-Arabi, 2006). There is strong evidence that working is generally good for physical and mental health and well-being as it takes into account the nature and quality of work and its social context (Waddell & Burton, 2006). However, the review of the above studies concludes that unemployment rates in working-age patients with ESRD undergoing HD are high compare to the general population. Unemployment among HD patients may have greater impact on their families' financial situation.

According to MDTR (2012), the federal and state governments were the main payer for new and existing ESRD patients who received HD therapy in government, NGO and private HD centers. Self-funding for HD was only about 22 to 23% (Lim, Ong, & Goh, 2012). I also realized that some HD patients in NGO and private HD centers received Social Security Disability Living

Allowance (Pencen Ilat) from SOCSO, whereas some patients in my working place received financial assistance from the Community Welfare Department. There were no studies reporting the financial implications of HD patients in Malaysia. However, patients with HD experienced financial difficulties and constraint were reported in numerous studies from other countries (Mok & Tam, 2001; Smith & Soliday, 2001; Ko, Lee, & Shih, 2007; Arefzadeh, Lessanpezeshki, & Seifi, 2009; Louis, 2010; Shih & Honey, 2011).

Mok and Tam (2001) reported financial difficulty was the most serious stressor, especially among the lower income Chinese patients on HD in Hong Kong. There were 24 (48%) out of 50 patients who reported a decline in family income resulting from losing their jobs due to physical restriction, their illness, the time needed to attend HD and associated care. In another study, Ko, Lee and Shih (2007) found that HD patients in Taiwan also faced financial constraints due to limited opportunity to earn extra money. Windhoek, Namibia, Africa and Louis (2010) found most of the self-paying patients or those patients whose HD were paid by medical fund experienced financial constraints due to medication and treatment expenses, transport expenses, and salary implications. Special dietary requirement that patients have to be compliant with is a hidden cost because buying special foods is more costly than the standard diet. This fact is also been acknowledged by the Fresenius Medical Care Group that some patients were unable to be compliant with medication when they encountered periods of limited funds (Fresenius Medical Care South Africa, 2008).

Another study reported that the full medical insurance coverage was available to all patients with ESRD in Iran. However, transport expenditure back and forth from the haemodialysis unit added

to the financial constraint as they were relying on taxis as a means of transport (Arefzadeh, Lessanpezeshki, & Seifi, 2009). Shih and Honey (2011) reported similar financial difficulties among Maori and their whänau/families in Northland. The cost of attending numerous specialist appointments, prescriptions and maintaining a healthy renal diet were all note to have a negative impact on finances. Smith and Soliday (2001) reported that the cost of disease-related medical expenses could lead to serious financial implications to some patients, as they may need to sell their houses. All these physical and socioeconomic effects of HD could lead to psychological and emotional problems.

2.5 Psychological and emotional effects of haemodialysis

Numerous studies reported ESRD patients faced many challenges, physically, emotionally, socially as well as financially while undergoing HD treatment that caused them to feel depressed (Polner *et al*., 2011; Shih & Honey, 2011; Theofilou, 2011; Yodchai *et al.*, 2011; Theofilou, 2012e). ESRD patients suffered from the disease complications resulted in frequent hospitalizations, disrupts their lives as well as their families' that would lead to psychological effects, such as depression and suicide (Sensky, 1993).

Depression is found to be common in HD patients. Depression has been reported as being the most prevalent psychological problem within HD populations in a vast amount of research (Finkelstein, & Finkelstein, 2000; Caress *et al*. 2001; Akoochekian, Ebrahimi, & Samooei, 2002; Cukor, Peterson, Cohen, & Kimmel, 2006; Karamanidou *et al.*, 2009; Chen *et al.*, 2010; Polner *et al,*. 2011; Shih & Honey, 2011; Yodchai *et al.*, 2011). The prevalence of depression among HD

patients reported in the United State of America was around 15% (Hedayati, Yalamanchili, & Finkelstein, 2012), whereas in the Islamic HD population was 43.1% (Bayat, Kazemi, Toghiani, Mohebi, Tabatababaee, & Dibi, 2012). In Saudi, 75% of HD patients and 33.4% of their caregivers were been found to be moderately to severely depressed (Saeed, Ahmad, Shakoor, Ghafoor, & Kanwal, 2012).

Besides that, depression was been found positively related to fatigue. Polner *et al.* (2011) found fatigue led to difficulties in performing basic activities of daily living and were associated with the presence of depressive symptoms. As a result, this psychological distress could further increase the functional disability and non-adherence to diet and medication of the patients. HD patients who are depressed and stressed have high rates of non-adherence to diet prescription as reported (Cukor, Peterson, Cohen, & Kimmel, 2006). In addition, a systematic review of 44 studies done by Khalil and Frazier (2010) found that depression had an adverse effect on adherence to dietary prescription, with non-adherence rates amounted to approximately 50%. Cruz, Almeida, Fleck and Polanczyk (2009) commented that depression was strongly associated with poorer prognosis, health status, and quality of life. Depression associated with impaired health related quality of life among HD patients were also been reported in other studies (Clearly & Grennam, 2005; Weisbord *et al*., 2005; Chen *et al*., 2010; Theofilou, Synodinoua, & Panagiotakic, 2013). HD patients who were depressed have high rates of non-adherence to diet and fluid prescription were reported in few studies (Cukor, Peterson, Cohen & Kimmel, 2006; Cukor, Cohen, Peterson & Kimmel, 2007; Khalil & Frazier, 2010). Patients who experienced anxiety and depression can lead to mental health problems, thus reduced quality of life and subjective well-being. This was report in several studies (Yeh & Chou, 2007; Kohli, Batra, &

Aggarwal, 2011). Thus, patients' ways of coping with stress and depression are important because it can contribute to greater morbidity and even to earlier mortality (Finkelstein & Finkelstein, 2000). Theofilou (2011e) reported that exercise programs might also be effective at reducing depressive symptoms in these individuals. Besides that, social support is also an integral way of providing better healthcare for patients with ESRD. Integration of psychological and material support for better healthcare of the patient is the essence of the social support system.

Anxiety is also common in HD patients. Cukor, Coplan, Brown, Peterson and Kimmel (2008) demonstrated that 27% of 70 urban HD patients had anxiety, which was somehow higher than the 18% incidence reported in a National Comorbidity Survey Replication (Kessler, Berglund, Demler, Jin, Koretz, Merikangas, Rush, Walters & Wang, 2003). Anxiety is a normal reaction to stress but extreme anxiety could lead to mental health problem and reduced quality of life and subjective well-being of the HD patient (Kohli, Batra, & Aggarwal, 2011). There were various studies that supported the findings (Cukor, Peterson, Cohen & Kimmel, 2006; Kimmel & Peterson, 2006; Cukor, Cohen, Peterson & Kimmel, 2007; Cukor, Coplan, Brown, Friedman, Cromwell-Smith & Peterson, 2007; Sousa, 2008).

From the literature reviews, many factors were been found to have caused HD patients to have stress, uncertainty and fear. Shih and Honey (2011) reported the Maori patients stated time spent on HD treatment and the long travelling needed to go for HD have affected their quality of life, and was very stressful for them. Mok and Tam (2001) in Hong Kong, and Logan, Pelletier-Hibbert and Hodgins (2006) in Canada reported that the patients viewed limited fluid intake and restriction on diet as a main stressor. Yodchai *et al.* (2011) in Thailand found patients often felt

stressed and depressed about the uncertainty of their health. They also reported other psychological stressors such as fear of dying, loss of control, changed self-image, dependency, worries about stigma, anger and isolation. Lok (1996) reported limitation of physical activity was the most troublesome stressor followed by decreased in social life, uncertainty about the future, fatigue and muscle cramps. Uncertainty about the future, fear, thinking about dying and death also featured in many interviews of HD patients in other studies (Polaschek, 2003; Sadala & Lorencon, 2006; Kaba *et al.,* 2007; Tong *et al.,* 2009; Herlin & Wann-Hansson, 2010). Kaba *et al*. (2007) revealed that patients in Greece felt uncertainty related to health instability and the necessity to rely on HD as a form of life-sustaining treatment. Some patients perceived lack of control over the course of the disease due to their progressive, debilitating health status with frequent acute illness episodes. All patients became anxious and even fearful as they contemplated potential problems, including the possibility of premature death.

Besides that, Herlin and Wann-Hansson (2010) in Sweden in a study of nine HD patients between 30 and 45 years of age found they experienced different sorts of fears evoked by HD treatments. Patients were afraid of the pain created by dialysis needle and contracting other disease. All patients were worried about the failure of AV fistula. On the other hand, Moran, Scott and Darbyshire (2010) reported that patients with HD felt uncertain, as they did not know whether they would get a new kidney or not. Although many patients in this study were hoping for a kidney transplant, they were afraid of the transplant surgery, and the medication following the transplant. They were also worried about the complications after the transplant, such as rejections of the transplanted kidney.

Majority of ESRD patients on HD developed negative psychological and emotional reactions.

However, some patients expressed positive psychological reaction towards HD. Sadala and Lorencon (2006) found that ESRD patients in Sweden appreciated the benefits brought by HD. This was because they felt much better, had improved physical well-being and quality of life as they could perform normal functions like walking and doing household chores after starting HD. Calvey and Mee (2011) found patients in Ireland developed greater appreciation as they felt that this was the second chance of life gifted by HD treatment while realizing that life was fragile and could be lost very quickly.

2.6 The effects of haemodialysis towards family

The time required for HD treatments and numerous treatment related symptoms have a profound effect on patients' family leading to alteration of roles in family, and change of family and social relationship (Wadd, King, Bennett & Grant, 2011). Smith and Soliday (2001) also revealed that ESRD patients were been burdened by their illness, the time required for their treatment and fatigue, decreased their capacities to provide physical and emotional care for their children. Their capacities in providing psychosocial cares such as engaging in play activities and school activities with their children were been compromised due to less time, effort and energy available. Smith and Soliday (2001) found that fatigue was more prominent in women on HD and affected their ability to care for their families and undertake domestic chores. Lee *et al.* (2007) reported similar findings among patients in Taiwan. Patients on HD also recounted their inability to participate in strenuous activities such as camping with the children and family, as well as non-attendance at family activities that occurred during their HD treatment (Al-Arabi, 2006).

ESRD patients experienced multiple positive or negative relationship changes due to their renal failure and HD treatment (Wadd, King, Bennett & Grant, 2011). Some patients talked about support from their family and enhanced personal relationships (Caress *et al.* 2001; Tanyi & Werner, 2008). These changes of family and social relationship among HD patients are also report in other studies (Calvey & Mee, 2001; Sadala & Lorencon, 2006; Molzahn, Bruce & Shields, 2008; Herlin & Wann-Hansson, 2010). Patients found a new social outlet while attending HD as they had made good friends with both HD staff and other patients (Calvey & Mee, 2011; Herlin & Wann-Hansson, 2010). Some patients regarded the dialysis environment to that of a big family (Molzahn *et al*., 2008). However, some patients reported the negative relationship changes such as dependence on others like family members and children (Tong *et al*, 2009) and staff and caregivers (Sadala & Lorencon, 2006; Hagren *et al.*, 2001). In some studies (Hagren *et al*., 2001; Smith & Soliday, 2001; Polaschek, 2003), patients reported a change of balance in physical and emotional strength between patients and their partners due to the disease and HD. Subsequently patients' partner limited their own activities and supported the ill partner. Thus, their role and relationship in the family changed.

2.7 Different ways of adapting and coping with haemodialysis

Coping is a theoretical concept concerned with the multifaceted phenomenon of how humans think, feel, and act in a specific stressful situation, and it is been primarily seen as a process that aims to reduce the level of perceived stress (Lazarus & Folkman, 1984; Keil, 2004). Patients with ESRD applied different coping mechanisms with illness and HD treatment. The kind of coping mechanisms used depends on their personal experience, social support system, individual

beliefs, and availability of resources (Mok & Tam, 2001; Welch & Austin, 2001; Yeh & Chou, 2007).

The strategies used by patients on HD included problem-focused coping or emotion-focused coping strategies, or approach coping or avoidance coping strategies. In addition, patients used planning, making adjustments, prayer, belief in religion, mediation, faith in God, and living in hope to adapt and cope with daily life (Mok & Tam, 2001; Hagren *et al*, 2005; Sadala & Lorencon, 2006; Herlin & Wan-Hassan, 2010; Kohli, Batra & Aggarwal, 2011; Wadd, King, Bennett & Grant, 2011; Yodchai *et al.*, 2011).

Herlin and Wan-Hassan (2010) found that ESRD patients applied emotion-focused strategy to accept HD treatment by seeing the time spent in treatment as 'working time'. They also applied problem-focused strategies to handle the different fears arising from the HD treatment. They learned about the machine and the medications, made an effort to get knowledge about the HD treatment and been engaged in own treatment in order to gain a sense of being in control.

Some patients applied "approach" and "avoidance" coping strategies to cope with HD. In India, Kohli, Batra and Aggarwal (2011) reported 30 patients on maintenance HD applied both approach and avoidance strategies to cope with the effects of ESRD and HD. Approach coping is problem focused which reflects cognitive and behavioral efforts to resolve life stressors such as positive reappraisal, seeking guidance and support. Those who applied avoidance coping tend to be emotionally focused which reflects cognitive and behavioral attempts to avoid thinking about a stressor and its implication or to manage the effect associated with HD, such as acceptance or

resignation. Kohli, Batra and Aggarwal (2011) commented that behavioral attempts would help HD patients in getting new sources of satisfaction, and enhance the effectiveness of dealing with various problems in personal, familial, societal, and occupational disturbances.

Patients also applied "planning" strategy to cope with HD. Yodchai *et al*. (2011) found the five Thai patients planned activities between their HD treatments and excluded activities that would take too long to perform. They tried to plan their medical appointments to fit in with their working schedule, liaising with their employers as well as health care professionals and contact an HD center before going on holidays or extended family visits.

Making adjustment is another coping strategy applied by patients. Yodchai *et al.* (2011) revealed that patients made social and physical changes to adapt to the restrictions imposed on their lives. Martin-McDonald (2004) reported patients reformulate oneself and finding new meaning in his/her situation instead of having their lives filled with despair and facing an unacceptable future. Patients also developed a new appreciation for life as they considered they were lucky to be alived (Martin-McDonald, 2003). When patients became accustomed to their treatment, they took over responsibility to care for themselves (Hagren *et al.*, 2001). Hagren *et al.* (2005) found one patient actively participated in the insertion of the needles to cope with the feelings of vulnerability. The other patients made some changes in their life, including how they ate and planned their activities with the help of healthcare providers, family and friends in order to cope with ESRD and HD treatment.

HD patients are anxious, depressed, having suicidal idea and fear of dying. Yodchai *et al.* (2011)

found many Thai patients adapted to their stress and depression through their religious beliefs, superstitions and mediations. Thai patients tried to adapt by prayer or promising to become a monk or a nun for a short duration of time if their request for improvements in their health was been granted. Some patients gave gifts to the monks and the temple, did good deeds, released little birds, fishes and cows, gave alms, offered food to monks and helped others in the hope of having a better life. Meditation was been applied to improve energy levels, helped the patient concentrate, gave him a sense of control over his life and helped him relax. Religion helped patients understand the value of life and that suicide was not the right path. Besides that, Finnegan-John and Thomas (2013) found patients in London also depended on their faith in prayer, doing meditations, and having beliefs in a higher power by worshipping in church, temple or mosque to help cope with their disease. Their faith linked them to a religious community, offering a support network, and enabling them to keep an existential perspective over their condition.

Sadala and Lorencon (2006) also found HD patients in Brazil discussed their belief in God and the need for prayer to cope with feelings of intense grief and sadness because they had ended up adapting to the machine, and they might die anytime. They praise the Lord and pray for the machine, for the nurses and for everything. The patient believed that God can heal anything, could heal kidney, restored it, and made a miracle if He wanted to. Some Brazilian HD patients said belief in God and prayer provided them with hope, made them comfortable with and accepting their health status.

Many HD patients used hope as a coping method to better view their situation. A higher hope

predicted reduced anxiety, depression, symptoms and burden related to kidney failure, and improved mental health as quality of life (Billington, Simpson, Unwin, Bray & Giles, 2008). In the Republic of Ireland, Moran, Scott and Darbyshire (2010) described their experiences of living in hope while they waited for a kidney transplant. This hope allowed them to get through the days, weeks, months, and years until the waiting was finally over. Yodchai *et al.* (2011) found Thai patients also hoped for a renal transplant because they wanted to recover from their disease. Lindqvist, Carlsson and Sjoden (2000) found patients talked about fulfilling dreams and a sense of freedom after a successful kidney transplantation. They also expressed "the wish for normality" which revealed a desire to live as they did prior to HD treatments. The hope of receiving a kidney transplant was also been reported in other studies (Rittman *et al*., 1993; Hagren *et al*., 2001; Polaschek, 2003; Krueger, 2009, Mitchell, Farrand, James, Luke & Wyatt, 2009).

I realized that each of the above quantitative and qualitative studies revealed the experiences of how patients living with HD structured their personal views into a meaningful pattern. Some of the quantitative studies did not explore patient experiences in detail. Questionnaires with Likert scale only allow the participants to rate their answer in numeric figures. The participants' answers were been guided by the questionnaires. They were not been given the opportunity to express their perceptions, feelings or thoughts that were outside the scope of the questionnaires. Therefore, the participants' minds were not been explored in greater depth. In addition, the questionnaires were been constructed by the researchers and they contain information on which the researchers wanted but not the patients' perspective. It is important to obtain the meaning of patients' living experience in patient social context. Thus, a critical approach in a qualitative method is needed, in order to provide a framework to enable the researcher to articulate the

ESRD patients' experience by contextualizing it within the renal setting. Such approach could enable a synthesis of the insights from the studies, clarifying the various dimensions of the patient experiences and producing data that are of greater coherence, depth, and detail.

Although several qualitative studies had investigated the experience of patients undergoing HD in foreign countries that sought to understand the experience of ESRD patients living with HD, there were limited published studies found, that specifically focuses on this group of people in Malaysia. Hoothay *et al*. (1990, cited in Polschek, 2003) comment that "researcher views do not reflect the patients' reality. Quality of life is a truly subjective entity and can only be evaluated from the patient's perspective". Therefore, more understanding about the problems and challenges faced by patients who receive HD in Malaysia is necessary. This review established a need for further research to explore the experiences and needs of these patients in order to tailor the nursing care based on patients' perspectives, and not on the researchers' or health care workers' perspectives. Thus, this qualitative study research sought to understand and to learn from the patients experiences of their disease and their HD treatment.

2.8 Summary

From the literatures reviewed above, I found that there were a number of research studies carried out that explored the experiences of patients with ESRD receiving HD in other countries. These studies reported the challenges and adjustments faced by the ESRD patients on routine HD treatments. Physical effects, psychological distress, socioeconomic effects, alteration of family and social roles and relationship, loses, restriction and limitations,

dependency, and adapting and coping were the dominant themes found in the reviewed literature. The effects of illness and treatment, dietary constraints, time restrictions, losses, financial burdens, psychological strain of awareness of impending death, and many such factors impede the normal life and normal ways of coping among patients living with HD. Many HD patients also experienced fatigue, restriction, loss, depression, anxiety, fear and stress. Feelings of hope mentioned in few studies were been overshadowed by the tremendous amounts of negative uncertainties and adjustments facing by these patients. Hence, it is relevant to study the experiences of patients living with HD in Malaysia due to the increased numbers of patients and its differences in socio-cultural and health care delivery system from other countries. The next chapter will discuss the methodology of this study.

CHAPTER 3

METHODOLOGY

3.0 Introduction

This chapter presents the research methodology of this study. It includes the justification for using qualitative research method, a description of the research setting, sampling method, with inclusion and exclusion criteria, ethical considerations, data collection procedures and data analysis method. It also outlines how the trustworthiness of this study was been done. The chapter concludes with a summary.

3.1 Justification for using qualitative research method

Appropriate research method is been needed to examine research question in order to obtain appropriate knowledge development in the study (Weaver & Olson, 2006). I use qualitative, explorative and descriptive methods to explore the experiences of patients with ESRD living with HD. When little is known about the subjects, qualitative research method is an appropriate approach that can provide the researcher rich and detailed information that is often more difficult to obtain using quantitative methods (Morse & Field, 1996; Marshall & Rossman, 2006). Hartley and Muhit (2003) commented that this type of research is better for investigating subjective meanings within a culture, understanding attitude and beliefs, and unraveling the dynamic constructs of culture and social traditions.

The most effective strategy to ascertain the in-depth perspectives of others is through qualitative interviewing (Patton, 2002). During a face-to-face interview, perceptions and experiences of the patients themselves can be fully explore, discover and understood. Behaviors, understandings, actions and experiences are hard to measure using statistical analysis as in quantitative research. Instead, detailed written descriptions and explanations of the phenomena under investigation are been produced in order to understand the meaning that people attach to everyday life (Gillis & Jackson, 2002). This method also prevents any loss of in-depth information in an experiential world of a person whereby certain aspects such as human emotion and feelings cannot be measure by using measuring tools alone in quantitative method (Hill, 2004, cited in Watson & Bruin, 2006). Therefore, qualitative, exploratory and descriptive research method is the most suitable method to explore issues from the perspectives of the people with ESRD living with HD treatment, to find meaning that may or may not been known to the person who experienced it, and to describe the phenomenon through the composite narrative (De Vos, Strydom, Fouche, & Delport, 2005).

The reasons for choosing interview as a data collection method in this study was that this method would result in a higher response rate if compared to using a questionnaire. Many people who would ignore a questionnaire are willing to talk with an interviewer who is obviously interested in what they have to say. Besides that, I could ask questions at several levels to get the most information from the participants. This approach is unique to the interview. An interview questions guideline was been utilized with the combination of structured and unstructured questions could provide the depth and richness of the data and at the same time elicit data that are

comparable from one participant to the next.

3.2 Research Setting

This study was conduct in Kuching, the capital of the state of Sarawak, one of the thirteen states of Malaysia. According to the Statistics from Sarawak General Hospital in 2011, out of 1610 patients with ESRD in Sarawak, 571 (35.5%) patients underwent maintenance and regular HD treatment in Kuching. Out of these patients, 260 (45.5%) received HD treatment in five private HD centers, 235 patients (41.2%) received HD in three HD centers managed by NGOs, 15 in 3 office HD centers managed by some government department, and 61 of the patients received HDs treatment in one HD center in public hospital. As the ESRD patients in Kuching were receiving HD treatment from various HD facilities thus this study participants were recruit from few different HD centers in order to gain rich in-depth information as well as to avoid any information bias.

3.3 Sampling the study participants

This study used purposive and snowballing sampling method to recruit the eligible participants. Holloway and Wheeler (1997) stated that purposive sampling is often use in qualitative research, as it enables the researcher to select participants who are most likely to increase the understanding of the phenomena being studied. This purposive sampling method was been chosen because it involved conscious selection of certain subjects or elements in the study by including "typical" participants or situation so that accurate and precise information can be collected from the participants (Burns & Grove, 2005). Besides, snowballing or network

sampling method was also used as it would enable me to locate participants from a network of other HD staffs who work in public, NGO and private HD centers in Kuching, Sarawak, as well as those referred by the patients who had participated in this study. Polit and Beck (2006), and Speziale and Carpenter (2007) recommended that only persons who had rich experiences were able to provide relevant data to the researcher. Thus, using these two sampling methods, patients who suffered ESRD and living on routine HD treatments were been selected.

Before I started my fieldwork and data collection, I contacted the staff in-charge of the eight HD Centers in Kuching through telephone to explain the purpose of the study, then, followed by the letters to seek for permission from the board of management of the respective centers to recruit their patients in the study. Out of eight HD centers in Kuching that I approached, only four HD centers gave permission to recruit their patients as participants. Thus, I had recruited patients from Renal Life Dialysis Centre, Pusat Dialysis Cahaya, KAS-Rotary-National Kidney Foundation Kuching, and Sarawak General Hospital (SGH) as my participants. The inclusion criterias for the study participants were: (a) Patient with ESRD who received regular HD for at least six months (regular identified as three treatments a week lasting 3-4 hours each treatment); (b) willing to participate; (c) adults aged from 18 to 65 years; (d) able to give informed consent and (e) able to understand and communicate in English or Malay or Mandarin language. The reason for the first criterion was to avoid data collection from participants during the "honeymoon' period. The honeymoon period lasts for between 6 weeks and 6 months (Reichsman & Levy, 1972). During the honeymoon period (one to three weeks after the start of HD), the patient would show a marked improvement both physically and psychologically, a relative increased in optimism and a relative lack of perception of restriction and limitation

associated with HD which might influence their perception. The exclusion criteria included those patients who were hospitalize in the past three months, been unfit, either physically or psychologically, according to the assessment of a doctor or a nurse and myself.

I have chosen the adult patients who met inclusion criteria in HD center at SGH. The nurse in charge at private HD centers (Renal Life Dialysis Centre and Pusat Dialysis Cahaya), and NGO HD center (KAS-Rotary-National Kidney Foundation Kuching), helped to recruit the participants from their HD centers.

3.4 Ethical consideration

Adherence to research ethical principles is important in order to protect the human rights of the participants (Burns & Grove, 2005). Prior to conducting the study, the ethical approval was been obtained in several stages. The proposal for this study was approved by Ethical committee of the Faculty Medicine and Health Science at the Universiti Malaysia Sarawak (UNIMAS) (refer to Appendix A), and Medical Research & Ethic Committee, National Institute of Health, MOH of Malaysia through Clinical Research Centre, SGH, Kuching (refer to Appendix B). Once all the ethical clearances were obtain, permission to conduct this study was seek from the Director and Head of the department of the HD Center at SGH, board of management of the five private and three NGO HD centers in Kuching (refer to Appendix C for a sample of letter to seek permission to invite the patient as participant). Appendix D, E, F and G are letters of approval from these centers to recruit participants.

For the patients who met the inclusion criteria and showed interest, the verbal and written, informed consent were obtained from the participants after they had read or understood all information about the research study (Appendix H in English version or Appendix I in Malay version). Informed consent was been taken to ensure that these participants had adequate knowledge and understanding of the information in the study and voluntarily agreed to participate in this study (Bernardo, 2009). I explained to the participants the purpose of the research, research procedures, its potential risks, benefits as well as the alternatives available by using the most appropriate language to ensure accurate understanding. This was to ensure the participants understood the information given and make a voluntary decision to participate in this study. They were also been informed of their rights as a participant such as the right not to participate and the freedom to withdraw from the study at any time without affecting their relationship with the researcher or the HD centers. After the informed consent was obtained, participants completed the demographic data (refer to Appendix M) prior to the interview process.

Besides that, permission to record and audio-taped each interview session was also obtained from the participants. I assured them that the use of anonymity to maintain the confidentiality in the research study. They were been given a pseudonym name in the transcripts and file notes. Name and information collected from the participants were only confided to my supervisors and myself. Only I knew their real names and contacting addresses. Any names of the people and the institution or organizations mentioned in the interview would be confidential as well. Participant clinical information obtained for the purpose of this study remained confidential and it was not possible to identify the names or individual details of the participant based on any publication or presentation arising from this study. Transcripts and file notes were kept in locked filing

cabinets accessible only by me. Computer files were password protected and would be destroyed five years after the paper completion of the study. I also considered the rights, safety and well-being of the participants more important than my interests in research.

3.5 The interview question guideline

An interview question guideline with open-ended questions was been generated as a tool or an instrument to gather data from the participants. This interview question guideline was been derived from my past and present reflection of professional experiences in nephrology nursing, as well as a thorough review of the published literatures, research questions and research objectives. The question guide included main questions with probing and clarifying questions to increase my understanding of the patients' experiences living with HD. I further revised the guide many times before and after the pilot study until it was approved by study's supervisors. An expert consultant nephrologist also reviewed the question guide. This process of refining the question guide was a step take to increase the validity of the study instrument.

The questions in the interview question guideline were design to explore life experiences of the participants living with HD, the impacts of HD on them and their family, and the coping strategies used to overcome the impacts. However, there was no question used in the actual study to explore the impact of HD on sexual life. This was because the participants in the pilot study shown discomfort and were not so willing to discuss much on this sensitive question. According to Hatch (2002), effective questions for a qualitative study will explore the participants' perspectives, be clear, open-ended, neutral, respectful of the participants' knowledge, and

generate answers related to the objectives of the research and the review of the literature. The interview questions asked in this study met these criteria.

Besides that, the purpose of using this interview question guideline was that pre-determined questions served as guidelines in order to smoothen an interview process and to ensure no important question was missed (Zabidah, 2010). The interview question guidelines were prepared in three languages: English, Malay and Mandarin version. It consisted of two sections. In Section A, questions consisted of demographic details included race, age, gender, marital status, history of illness, and length on HD. Section B consisted of questions that explored the experience of ESRD patients living with HD treatment, problems encountered by these patients, the impacts of HD treatment, and how they coped with the challenges. A copy of the interview question guideline can be found in Appendix J for English version, Appendix K for Malay version, Appendix L for Mandarin version.

3.6 Pilot Study

A pilot study was been conducted prior to the actual data collection. It was been done on five patients receiving HD at SGH. These five participants were been excluded from the main study. The aim of the pilot study was to test the clarity, reliability and appropriateness of the interview questions. This would allow me to adequately tailor the interview questions so that it can be well understood by the research participant, also to train and prepare myself with the interview session. The opinion and suggestions obtained in the pilot study were been used to modify and improve the interview question guideline. As the participants were not comfortable with the questions that

aimed to explore the impact of HD treatment of sexual life, so those questions were eliminated from the interview question guideline (refer to Appendix M).

3.7 Data collection

Data was been collected for five consecutive months from June to October 2012. Face-to-face interview was been conducted in the four selected HD Centers in Kuching, Sarawak. A number of 28 interviews were conducted. Five interviews were been conducted in SGH, ten interviews within two private stand-alone HD centers (Renal Life Dialysis Centre and Pusat Dialysis Cahaya), whereas thirteen interviews were conducted in one NGO based HD center (KAS-Rotary-National Kidney Foundation Kuching) where the patients received their HD treatments.

The participants were free to choose the venue for the interviews. Interviews were been conducted in a setting of their choice, and at a time of their preference. This is to ensure that participants were comfortable and to facilitate the exploration of their experiences and feelings. All participants were offer the opportunity to be interview in a private room. However, some of them prefer to be interview in the HD center while they were receiving HD treatment. Eleven of the participants were been interviewed in the counseling room or isolation rooms at HD centers before and during dialysis, whereas 17 participants were interviewed during the HD session.

Before the interview session, I arranged the chairs with adequate space between the participants and myself, which was not too near to participants, but far enough for me to communicate, and observe the participants' facial expression and body posture. This was to ensure the interviews

were undertaken in a conductive environment and to avoid entering the participants' personal space that could cause discomfort and in turn, might negatively influence the data collection process.

All the interviews were conducted by myself as this would allow me to probe further when there were any doubts. This was the appropriate way to obtain first-hand information from the participants to enhance the knowledge and understanding of patients' experiences (Zabidah, 2010). The interviews were conducted depending on the participants' preferred language either in English, Malay or Mandarin. Most of the participants spoke Mandarin and Malay, however, some participants spoke in English mixed with Malay and some spoke English mixed with Mandarin. Allowing the participants to use the languages that they were familiar allowed them to express their feelings freely and thoroughly. As I am familiar with these three languages, no translator was required for the data collection.

I usually conducted one interview only per day. However, sometimes I had to conduct two or three interviews when the participants who I had been interviewing referred other interested patients to me. I took between 44 and 90 minutes to interview each participant. All interviews were audiotape to prevent any information loss and to ensure accuracy.

Prior to the commencement of an interview, I usually started with greetings and chatting to gain rapport with the participants. At the same time, I gather socio-demographic data from the participants to complete section A in the interview question guideline. I also informed participants their rights as participants, the purpose of the interview session and confidentiality.

Then I obtained written informed consent from all of the patients who participated in this study.

My first interview was conducted in an isolation room at a public HD unit with a 49 year old Malay lady while she was receiving HD. I was familiar with this lady who had failed renal transplant and had received HD treatment for the past eight years. When she was ready to be interviewed, I started my first interview question with "Can you please describe your experience of living with regular haemodialysis treatment?" Further questions were open ended to gather more information from the participants was encouraged to share stories and more in-depth experiences living with HD. There was an allowance for flexibility during the interview, even though the questions were based on the interview guide. I listened carefully and attentively to what she said. My interpretation and understanding of her experience began during the interview. To avoid the risk of ending up confirming my own frames of reference, four probing strategies were used, repeating; request for clarification; request for elaboration; and request for confirmation (Abrandt, 1997). When clarification was needed, I prompted further with probing or other relevant questions in order to understand more about her experiences. If I had doubts about what she said, I would confirm with her by repeating what she said. This counterchecking with participant was necessary in order to ensure that what was interpreted was from the participants' perspectives (Marshall & Rosman, 2006; Holloway & Wheeler, 2010).

Non-verbal information is important as it could help to identify the hidden meaning that might be significant in the data analysis (Gerrish & Lacey, 2006; Holloway & Wheeler, 2010). Thus, during the interview process, I also made some field notes. Field notes were mainly observational, theoretical and personal. The observational notes were descriptive and

concentrated on the factual details of the interview situation, while the theoretical notes attempted to derive meaning from the observational notes. The personal notes were descriptions of my own reflections, reactions and experiences (Wilson 1989). I made some field notes about the non-verbal expression that I observed from the participants. For example, facial expression of sadness or shedding of tears that was interprete as sad feeling. Then I explored further on what made them feel sad and why they were sad.

That interview session lasted for 85 minutes. Before I ended my interview; I summarized what the participant expressed, and asked her "Is that what you mean?" Lastly, I ended up with one question "Is there anything else that you would like to say about life with HD treatment?" I did not rush to stop any interview; if she told me new things, I would probe further again. If there was no new information, then I would stop the interview and thanked the participants for her contribution. I also informed her that I would probably contact her again, if necessary, to make clarifications after this interview, either by telephone call or another shorter period of interview. Transcribing verbatim was been done on the same day, as I was very anxious to know my findings in order to help my subsequent interview.

While I continued to interview the subsequent participants by repeating the above interview process, I encountered a few problems during the interview process. For example, my second and third interview was conduct with two Chinese male patients before the HD session at an NGO HD Centre on the same day. The nurse in charge of that centre chose them and arranged a private room for me to conduct the interviews. The second interview lasted for 90 minutes, but the third interview only lasted for 50 minutes. The third participant expressed less regarding his

life with HD with some statement like “everything is just fine”, “okay”, “not much problem”. I realized that the participants who were familiar with me tended to tell me more about his or her feeling but those who were not familiar with me might have difficulty to share their inner feeling. Therefore, for the subsequent potential participants in NGO and private HD units, I spent time with them before or during their HD session in order to establish a relationship with them. If the potential participants expressed willing to share their experience, then I invited them to be interview.

Some participants requested to be interviewed during the HD session after they had read through the interview question guideline. After I obtained permission from my study supervisor, I interviewed them while they were receiving HD treatment, with only occasional interruptions by registered nurses to collect data on the functioning of the HD machines.

Besides that, there were four participants (one man, three women) who showed their sadness by shedding their tears when they recalled their pain and sad experiences during the interview. I had expected these negative emotional feelings from the participants while being interviewed. I offered them tissue papers that I had prepared earlier and gave them sufficient time to calm down. The interview process would continue if the participant was able to calm down. Unfortunately, one unmarried participant requested to discontinue the interview session after 44 minutes of interviewing as she was unable to control her emotion, but the other three participants completed the interview sessions.

Analysis of data began when I listened to the participant verbal description of their experiences

and observed their nonverbal body language during the interview as recommended by Speziale and Carpenter (2007). After each interview, I transcribed the interview data as soon as I could to prevent any loss of important information. The analysis of the first three interviews revealed some preliminary categories and dictated the direction and nature of further data collection. The category of dependence emerged from early interviews and, as it seemed to have significant impact on the patients' life, this concept was pursued further by asking how the dependence impactes their family life and relationships. Further data collection was guide by gaps and questions in the emerging categories. After 24th interview, I found the new information decreased. I continued the interview until the participants' responses became repetitive. I stopped collecting data once no new information was obtain from new participants and data obtained was sufficient to describe the experience being studied (Polit & Beck, 2006; Cohen, Kahn & Steeves, 2000). The data saturation was reach after the 28th interviews.

3.8 Data analysis

Data analysis was been done manually with close guidance of my supervisors. My analysis was aimed to provide greater ‘depth’ and ‘meaning’ in the remarks made by HD patients in this study. Thus, an interpretative thematic analysis method was need for analyzing transcribed data in order to describe the patients’ individual experiences of living with HD in depth. The analysis method was adapted from Zabidah (2010) with her permission. This analysis method was chose as I felt it was more relevant in my context and I can detect the repetitive concepts or themes while listening to the audio tapes. I also felt that Zabidah (2010)’s analysis method has a clear structure and in its most comprehensive sense, which referred to the totality of life experiences belonged to

a single person.

Zabidah (2010) analysis process consists of nine steps to manage collected data which focused on the identification of a core category and themes related to the research questions and objectives. Figure 3.1 shows the sequence of the data analysis.

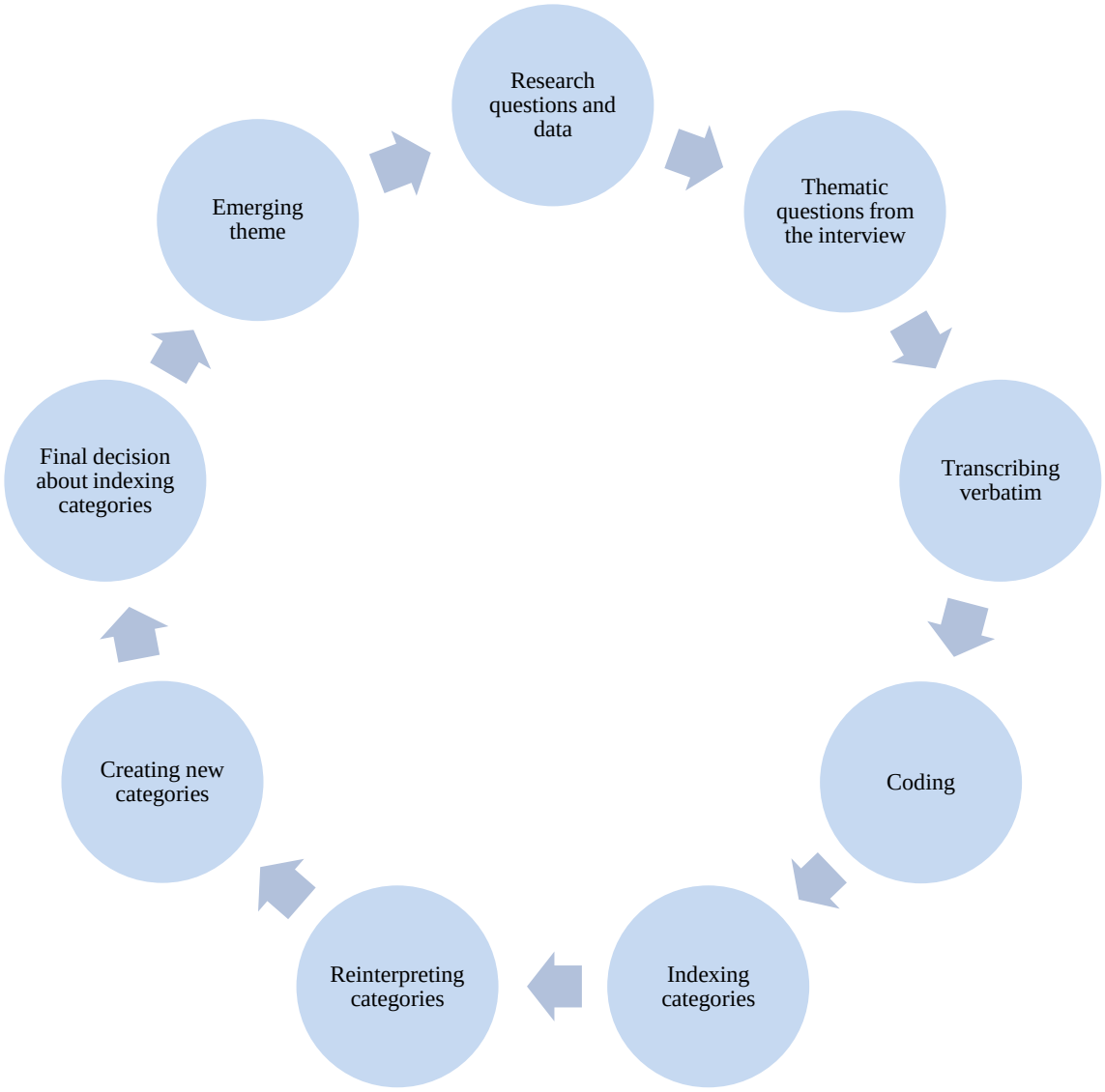


Figure 3.1: The sequence of data analysis process (Zabidah, 2010, pg. 93)

These nine steps analysis processes started with ‘research questions and data’, follow by ‘thematic questions from the interview’, ‘transcribing verbatim’, ‘coding’, ‘indexing categories’, ‘reinterpreting categories’, ‘creating new categories’, ‘final decision about indexing categories, and ‘emerging themes identified’.

3.8.1 Research questions and data

First, the research questions were use to guide the data analysis process according to the thematic questions from the interview.

3.8.2 Thematic questions from the interview

Second, the thematic questions from the interview questions guideline in this study were develope according to the research questions under these four themes: life experiences of living on HD, impact of HD towards patients, impact of HD towards family, and coping mechanisms.

3.8.3 Transcribing verbatim

The third step was to transcribe the data collected. I transcribed all data verbatim. As I am fluent in the three languages, Mandarin, Malay and English used in the interview, I did not require an interpreter to transcribe the interview data. This step was the most time consuming and most challenging part for me, especially some of the participants used mixed languages in one single interview.

Initially, all (28) the audio-taped data were listened to and transcribed verbatim into the language spoken by the participants, namely English or Malay or Mandarin. This was to keep the originality of the meaning or essence described by the participants. The transcribed interviews were read without structure and with repeated occasions until I gained a sense of the whole. Field notes were use to make clarifications of the transcripts, and nonverbal data were add with interview data verbatim to produce a written description of the experience.

The first transcriptions were, then, been translated from either Malay or Mandarin into English language and the typed using Microsoft Word. These text files were been checked against the original audiotapes and field notes to ensure the transcription was close to the data.

3.8.4 Coding

In the following step, I created a table in Microsoft word with four columns, as adopted from Zabidah (2010), using heading 'dialogue, code, keynote and interpretation' (refer to Table 3.1). I transferred interview verbatim data from transcripts in the column of 'dialogue' for each participant. I focused on the discrete phrases and sentences, and asked myself "What were these participants trying to tell me?" In doing this, I tried to find out the part of the text that revealed the phenomenon been studied. The significant word in the statements were brought into 'keynotes' column, whereas, my understandings of the meaning of the significant statements were written in the 'interpretation' column in the table. I realized that the meaning of the text was interprete as a whole; and phrase, sentences and the text are interrelated.

Then I identified the consistencies in participants' statement and grouped together repetitive patterns. I gave a code to each of these patterns and put under the 'code' column in the table (Table 3.1). I continued to interview other participants, transcribed data and repeated the above process for each transcript. Refer to Table 3.1 for a sample of the transcription, code, keynote and interpretation.

Table 3.1: A sample of transcription, code, keynote and interpretation

Dialogue	Code	Keynote	Interpretation
I have to receive dialysis treatment. That is the way to live. That is the best way can help me.	Depending on haemodialysis treatment	Dialysis treatment is the way to live.	Patient unable to live without dialysis
Every Tuesday, Thursday, Saturday, I must come to HDU [Haemodialysis Unit]. I never miss my dialysis treatment. If I don't have HD, I will have shortness of breath.	Depending on haemodialysis treatment	If not receiving HD, patients will have shortness of breath.	Patient was unable to live without dialysis.
I must come for dialysis. If I don't come for dialysis, I will die.	Depending on haemodialysis treatment.	If patients don't come to receive HD, the patient will die.	Patient was unable to live without dialysis.

3.8.5 Indexing categories, reinterpreting categories and creating new categories

Each piece of information was coded and compared with the other for similarities and differences in the experiences of those interviewed guided by the research questions. The similar codes that emerged were listed and clustered together. This was carried out by viewing the frequency of the excerpts, or how thoroughly, precisely and specifically an aspect was emphasized. Statements made by the participants that were consider significant were extracted and placed in categories through three steps, which included indexing categories, reinterpreting categories and creating new categories. In this way, a preliminary pattern of categories was constructed and tested against individual excerpts. If any new interpretations emerged, the categories were revised and separate excerpts were re-categorized. The preliminary pattern was scrutinized and subsequently revised into a final complex of categories. Thus, one category often includes a number of sub-categories or sub-subcategories at varying levels of abstraction (refer to Figure 3. 2).

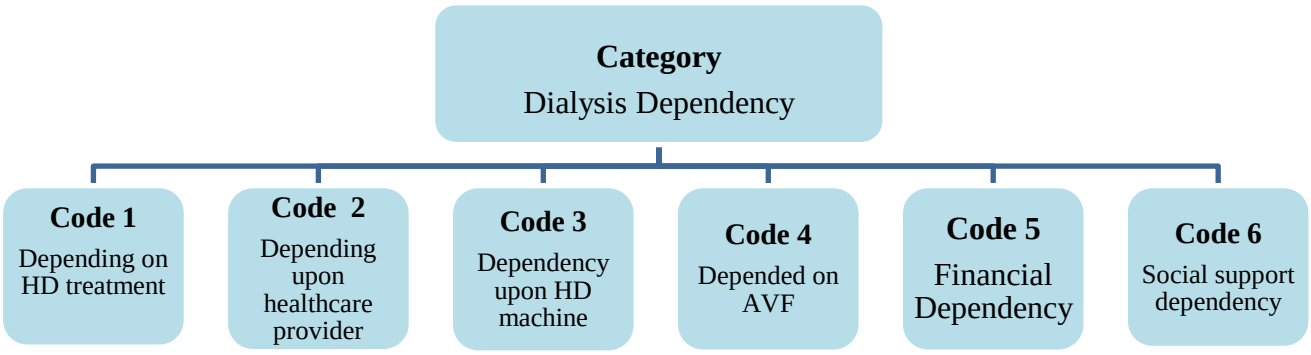


Figure 3.2: A sample of category and codes formation

3.8.6 Final decision about indexing categories

Lastly, the internal relationships between the categories were described. The final decision about indexing categories collapsed to create themes. The theme or themes were identified through a selective reading of the transcripts from the interviews and reviewing the audiotapes several times. (Refer to Figure 3.3 for another sample of categories and theme formation).

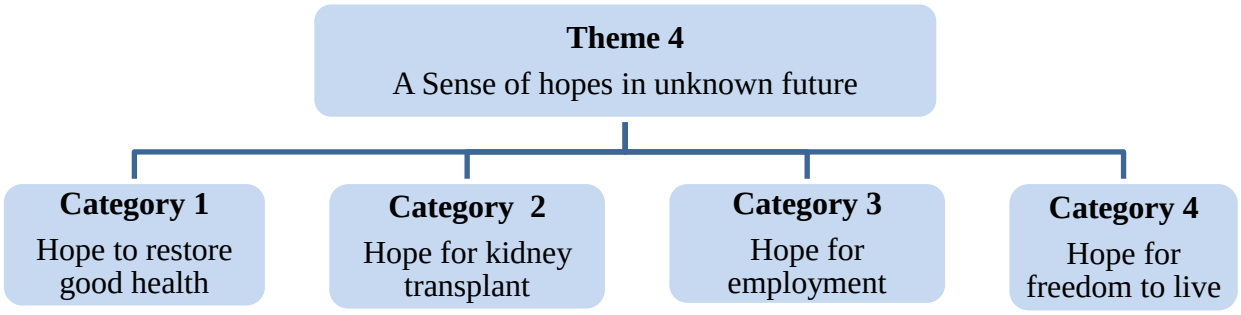


Figure 3. 3 A sample of categories and theme formation

3.8.7 Emerging theme

A descriptive summary of each theme was written and specific excerpts were being extracted from participants' statements as evidence. These themes were then, incorporated into the text describing the structure of the life experience of the HD patients, impacts of HD towards patients and family, and coping mechanisms applied by them. Later, the theme was translated to English for writing purposes. These themes, developed from the analysis were then validated with the

participants through telephone. If the participants disagreed with the themes and subthemes, the excerpts were re-categorized. I also discussed with my supervisors to examine the themes from the sources of the data a number of times until my supervisors were satisfied. (Refer to Figure 3.4 for another sample of the codes, categories and theme formation). At the end of the analysis, there were a total number of four themes, 13 categories and 61 codes obtained.

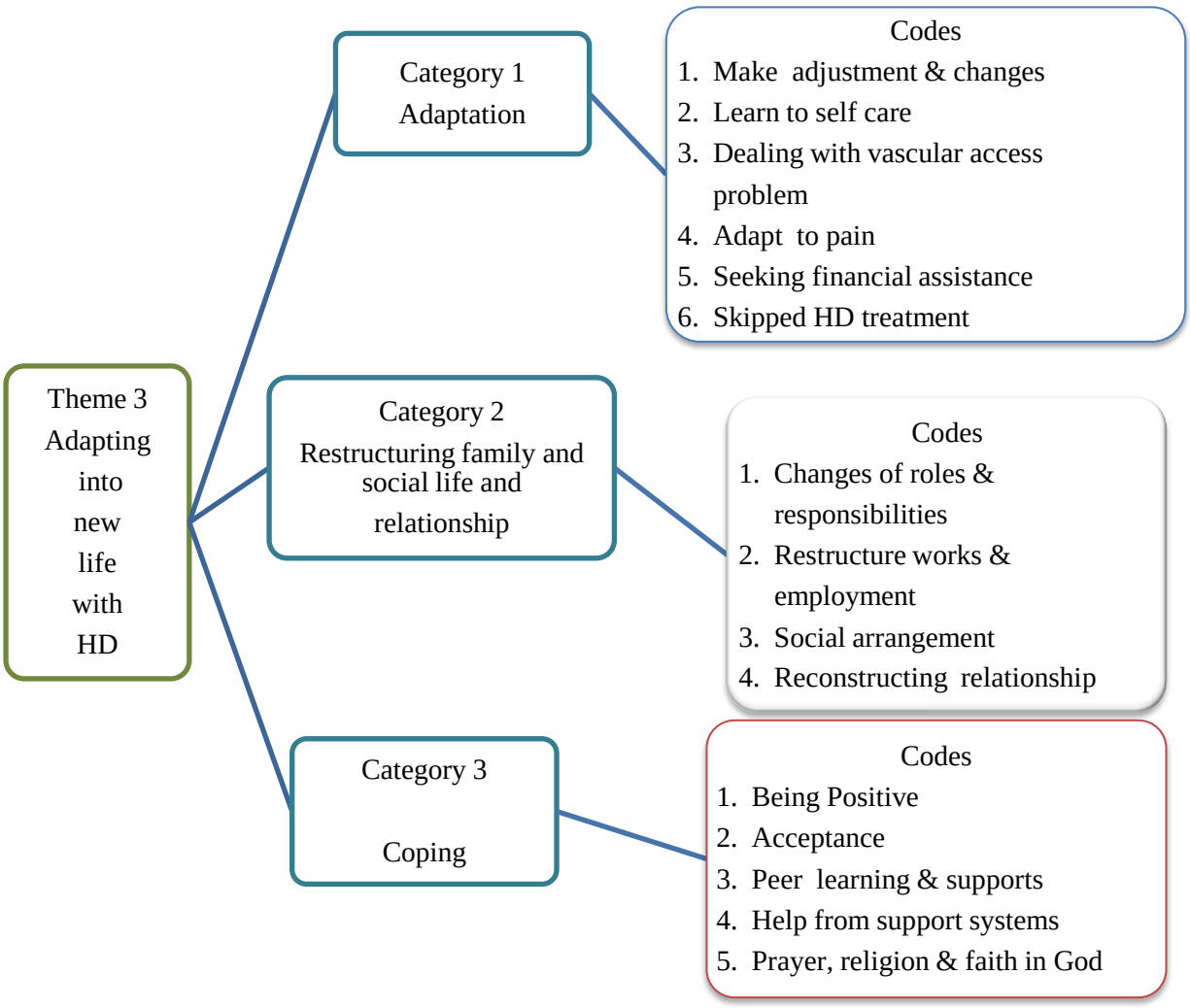


Figure 3.4 Diagram of codes, categories and theme formation

3.9 Ensuring Trustworthiness/Rigour of the study

Rigour in a quantitative research is demonstrated by the concept of validity and reliability. However, the term of trustworthiness is use to ensure methodological rigour in a qualitative research study. Rigour in qualitative research is demonstrated through researchers' attention to and confirmation of information discovery (Speziale & Carpenter, 2007). The goal of rigour in qualitative research is to accurately represent study participants' experiences. Thus, methodological trustworthiness must be address seriously to show its integrity and competency (Tobin & Begley, 2004; Koch, 2006).

The trustworthiness in a qualitative study is been endorsed based on its credibility, dependability, transferability and conformability (Krefting, 1991; Moules, 2002; Tobin & Begley, 2004; Koch, 2006). These four criteria are crucial to judging the rigor of qualitative research. Guba's model (cited in Krefting, 1991) was used to ensure trustworthiness. This model is been well-develop conceptually, and has been use extensively by qualitative researchers, particularly nurses and educators (Krefting 1991). The following section describes the strategies that I took to ensure credibility, dependability, transferability and conformability.

3.9.1 Credibility

Credibility is an evaluation of whether or not the research findings represent a "credible" conceptual interpretation of the data drawn from the participants' original data (Lincoln & Guba, 1985). Lincoln and Guba (1985) argue that ensuring credibility is one of the most

important factors in establishing trustworthiness. Thus, I applied various strategies to increase the probability of credible finding to address the internal validity in this study:

a) I adopted an appropriate and well-recognized data analysis method (Zabidah, 2010).
b) A pilot study was been conducted prior to the actual data collection to test the clarity, reliability and appropriateness of the interview questions. This had removed ambiguity and tested the adequacy of response categories.
c) Prolonged engagements with the participants, who were on HD treatments, were completed. I spent time to let the participants become acquainted with me and to form a trusting relationship with me.
d) I used different data collection methods, especially individual interview and observation with field notes to record the facial expression of sadness and shedding of tears. This non-verbal information was important as it could help to identify the hidden meaning that might be significant in the data analysis.
e) I participated in the research as interviewer, not just be an observer in order to get first-hand information. I probed further when there was any doubt. I applied four probing strategies: repeating; request for clarification; request for elaboration; and request for confirmation to avoid the risk of ending up confirming my own frames of reference.
f) The interviews were preceded by an unrecorded settling-down time during which the nature and purpose of the study was briefed.
g) The technique of "member checking" allowed me to see whether participants recognized the findings of the study to be true to their experiences. Such "member checks" sought feedback from the participants regarding the accuracy of the

interpretation. Those who had lived the described experiences validated that the reported findings truly represented their experiences. If there was a discrepancy, I returned to the data for further analysis and interpretation.

h) Regular meetings with my supervisors were conduct. The two study supervisors are senior nursing academicians in UNIMAS and had much experience in conducting qualitative studies. They had presented their studies at many conferences and published articles both nationally and internationally. They posed questions regarding the research questions, methodology, ethics, trustworthiness, and other research issues. I also discussed my findings and interpretation, codes, categories and themes with them. They provided critical comments and suggestions throughout the study process. Besides that, I presented my research findings and data interpretation to my supervisor and the postgraduate committee of UNIMAS for critique and evaluation. The suggestions and opinions offered by these experts helped me to develop new understanding and interpretation of the study data.

i) I attended research methodology workshop, data analysis workshop as well as seminar and workshop on qualitative interview to improve my research skills.

j) The patients volunteered to participate in this study were from different characteristic groups such as gender, age group, ethnic group, duration time on HD, education level, marital and employment status and different source of HD funding to provide their thoughts, beliefs and feelings.

k) I recruited participants from different organizations to provide a variety of perspectives in order to get a better and more reliable view of the reality.

l) I recruited participants from four different HD facilities managed by government,

private and NGO that had a different health care delivery system, policy and setting in order to gain rich and in-depth information.

3.9.2 Transferability

Transferability refers to the probability that the study findings have meaning to others in similar situations (Krefting 1991; Moules, 2002; Tobin & Begley, 2004). Merriam (2002) stated that transferability refers to external validity, which is concerned with the extent to which the findings of one study can be applied to other situations, or to a wider population. In a qualitative study, since the study sample is small, generalizability is never possible. However, Koch (2006) stated that the researcher must describe the original context explicitly so that the reader can judge whether the study can be transferred to another context. Moules (2002) commented that adequate contextual information enables the readers to view the study findings as meaningful and applicable in term of their own experience. In this study, the following steps were taken to ensure transferability:

a) A rich detail related to the context of the study was been provided in the introductory chapter of this thesis.
b) A detailed description of the data collection and data analysis methods in the methodology chapter were provided in order for other researchers to compare and trace the methods used.

3.9.3 Dependability

Dependability is an assessment of the quality of the integrated processes of data collection, data analysis, and theory generation (Krefting 1991; Moules, 2002; Tobin & Begley, 2004; Koch, 2006). Dependability addresses the issue of reliability of the study. It is met once researchers had demonstrated the credibility of the findings. Dependability cannot exist without credibility. I took few strategies to ensure dependability:

a) This study was conduct in Kuching, the capital of the state of Sarawak, one of the thirteen states of Malaysia. The information gathered from the participants in this study might not be the same as the information provided by other local foreign researchers.
b) A clear interview question guideline was been utilized for all participants in this study. A combination of structured and unstructured open-ended questions could provide the depth and richness of the data and at the same time, elicited data could be comparable from one participant to the next. This interview questions guideline was revise many times before and after a pilot study until approved by study's supervisors to obtain quality probing and clarifying questions to increase the validity of the study instrument.
c) An in depth face-to-face interview was chosen as a data collection method in this study because it resulted in a higher response rate if compared to using a questionnaire. I could ask questions at several levels to get as much information as needed from the participants in order to enhance knowledge and understanding of patients' experiences.

3.9.4 Conformability

Conformability measures how well the inquiry's findings are support by the data (Lincoln & Guba, 1985). It is a process criterion. In order to ensure conformability, the researcher would document all findings to leave an audit trail (Lincoln & Guba, 1985). This requires recordings of the activities occur during the study so that another individual could follow. The objective was to illustrate as clearly as possible the evidence and thought processes that led to the conclusions. I used the following steps to ensure conformability of this study:

a) The participants were recruited from four different HD facilities, not only from my working place to avoid any information bias from the participants. This was also to reduce the effect of researcher bias that might be influenced by my pre-understanding of participant's experiences.
b) The research committee of the Faculty of Medical and Health Sciences, UNIMAS approved my research proposal.
c) Critique and evaluation of my study by my supervisors, an expert consultant nephrologist, and the UNIMAS postgraduate committee provided me valuable comments and suggestions that helped me to develop an understanding and interpretation of the study data. Thus, the audit trail from all experts allowed for examination of original transcripts, data analysis documents, field notes, comments from member checks and the text of the dissertation itself allowed for conformability.

3.10 Summary

A qualitative, exploratory and descriptive approach was use to explore the experiences of patients with ESRD in Kuching while on HD treatment. This study was been conducted with the intent of gaining knowledge and understanding about life experiences of patients with HD treatment. Since little is known about the experience of Malaysian patients on HD treatment, a qualitative method would provide a platform for the exploration of the experiences of this group of patients. The research process of the study, which included setting, sampling method, data collection and data analysis were discuss. Ethical considerations and trustworthiness of the study were also elaborate in detail. The next chapter describes the study findings.

CHAPTER 4

STUDY FINDINGS

4.0 Introduction

This chapter presents the findings on the participants' social-demographic data, the emergent themes and subthemes. Participants' experiences were illustrat in four major themes: (1) Living with the paradox, (2) When life is dependent on haemodialysis, (3) Adapting into new life with haemodialysis, and (4) A sense of hopes in the unknown future. All names of participants, place and city in the descriptions of the themes, categories, and excerpts are pseudonyms to ensure confidentiality.

4.1 The participants

A number of twenty-eight (28) participants underwent HD treatments from one (1) public, one (1) NGO and two (2) private HD centers volunteered to participate in this study with 19 men (68%) and nine (9) (32%) women. Eleven of them were Chinese, seven (7) Malay, six (6) Bidayuh, two (2) Iban, one (1) Kenyah and one (1) Jawa. The participants' ages ranged from 28 to 63 years old. They had undergone HD from seven (7) months to 26 years. Among them, 18 (64%) were married, seven (7) (25%) were single, two (2) widowed and one (1) divorced. Only eleven (39%) of the participants were employed, seven (7) government servants, two (2) self-employed and two (2) working in the private sectors. The other seventeen were unemployed with three (3) of them

being housewives. Regarding the source of haemodialysis funding, thirteen were funded by government, nine (9), SOCSO, four (4), charitable bodies and two (2) were self-funded. Detailed information and demographic data about the participants is been presented in Appendix N. The characteristics of the participants are presented in number and percentage (refer to Appendix O).

4.2 Themes and subthemes

Four themes with 13 subthemes and 61 codes emerged after selective reviews of the transcriptions and audiotapes obtained from the individual interviews. The first theme was "Living with the paradox" with three (3) subthemes, "Dialysis was beneficial but problematic", "Mixed feeling of thankfulness and appreciation, but sadness and constant worry", and "Uncertainty and fear". The second theme was "When life is dependent on haemodialysis" with the three (3) subthemes, "Dialysis dependency", "Restricted life", and "Dialysis related losses". The third theme was "Adapting into new life with haemodialysis" with three (3) subthemes such as "Adaptation", "Restructuring family and social life and relationship", and "Coping". The final theme was "A sense of hope in the unknown future" with the four (4) subthemes "Hope to restore good health, attain pre dialysis status and live healthily", "Hope for a kidney transplantation", "Hope for employment", and "Hope for freedom to live". (Refer to Table 4.1 for total number of themes, categories and codes formation).

Table 4.1 Total number of themes, categories and codes formation

NO.	THEME	CATEGORIES	CODES
1.	Living with the Paradox	1. Dialysis was beneficial but problematic	1. HD removes the symptoms of ESRD 2. Still experienced physical side effects of HD treatments.
		2. Mixed feelings: (a) thankfulness and appreciation	1. Availability of HD machine 2. Availability of HD treatment 3. Availability of financial Assistances
		(b) sadness and constant worry	1. Having renal failure 2. Malfunction of AVF 3. Failure of water or electricity power supply 4. Guarantee of dialysis funding
		3.Uncertainty and fear	1. Unstable chronic disease 2. Prognosis and outcome of life 3. Death 4. HD treatment 5. Future 6. Kidney transplant - Long waiting time, - The complications, and - The restrictions following transplantation

2.	When life is dependent on haemodialysis	1.Dialysis Dependency	1. Depending on HD treatment 2. Depending upon the HD machine 3. Dependency upon health care professionals 4. Depended on AVF 5. Financial dependency 6. Social support dependency
		2. Restricted life	1. Diet and fluid intake restricted 2. Restricted time 3. Restricted work 4. Social restriction
		3. Dialysis related losses	1. Loss of physical strength 2. Loss of employment or earning capability 3. Loss of freedom 4. Loss of future
3.	Adapting into new life with haemodialysis	1. Adaptation	1. Make an adjustment and changes 2. Learn to self- care 3. Dealing with vascular access problem 4. Adapt to pain 5. Seeking financial assistance 6. Skipped HD treatment
		2. Restructuring family and social life and	1. Changes of roles and responsibilities 2. Restructure works and employment

		relationship	3. Social rearrangement 4. Constructing relationship
		3. Coping	1. Being positive 2. Acceptance 3. Peer Learning and support 4. Help from support systems 5. Prayer, religion and faith in God
4.	A sense of hope in the unknown future	1. Hope to restore good health, attain pre dialysis status and live healthily	1. Physical and emotional health improvement 2. Want to restores good health 3. Attain pre dialysis status 4. Live healthily
		2. Hope for a kidney transplant	1. Free from dialysis 2. Life will be more convenient 3. Less restriction 4. Better quality of life 5. Free to travel 6. Brighter future
		3. Hope for employment	1. Still want to work 2. Hope government offers a job 3. Earn more money 4. Make changes in financial status 5. More happy and luxurious life
		4. Hope for freedom to live	1. Freedom after a successful kidney transplant

			2. Freedom to travel with small, portable and wearable HD machine
Total	4 themes	13 categories	61 codes

4.3 Living with the paradox

The first theme identified was "Living with the paradox". This theme consisted of three (3) subthemes, "Dialysis was beneficial but problematic", "Mixed feelings of thankfulness and appreciation, but sadness and constant worry", and "Uncertainty and fear".

"Living with the paradox" was a theme indicated by an apparent paradox experienced by the participants caused by HD treatment. The participants talked about having both positive and negative physical effects of HD. All participants had highlighted that HD treatment was beneficial but problematic.

4.3.1 Dialysis was beneficial but problematic

The participants expressed the paradox of physical responses and experiences of HD treatment. All the participants admitted they had benefited from haemodialysis treatment as they felt much better than they did prior to starting HD. HD had relieved their symptoms such as breathlessness, nausea, vomiting, loss of appetite. As a whole, they felt their physical wellbeing had very much

improved as stated by the following participants:

> *"When my whole body swelled up like a balloon until I couldn't take it, I couldn't breathe, couldn't eat, couldn't move and sleep, I went for HD in a private dialysis center. After HD treatment continued for three days, I felt better. I could breathe, eat and move."*
>
> (Brian)

> *"When I drank more, my body swelled up. After dialysis, fluid was extracted from my body. I felt better."* (Faizu)

> *"Dialysis is definitely a good thing for me. After I had started on dialysis, I had not much problem everything became okay. I had appetite to eat. I didn't have swollen body, and difficulty in breathing anymore. Within these two years, I didn't experience fainting and vomiting. My condition was much better than last time. HD is good, useful and beneficial to me. It reduced my difficulties."* (Oscar)

However, majority of the participants asserted that although it was beneficial, they also experienced the side effects of HD treatments such as hypotension, leg cramps, abdominal cramps, headache and fatigue. They felt more tired on the days they underwent HD treatment. They experienced fatigue which was reduced their physical and functional capabilities. They stressed that their ability to carry out everyday chores, such as managing their personal hygiene, cooking, cleaning and other daily living activities were been affected. The participants reported

that they felt weak and tired after HD treatment. Sometimes this would last for only a few hours while sometimes required a good night sleep to recover:

> *"After completing dialysis, I got headache, vomiting and giddiness… //.... I was tired. I could not do anything."* (Brian)

> *"When too much fluid extracted from my body, I felt giddy, leg cramp, sometime also had abdominal cramp. I needed to rest at home."* (Faizu)

> *"When I was giddy and tired, I would lay down after I reached home. I could not do any household chores. Only on non- dialysis day, I could do my cooking."* (Aisyah)

> *After dialysis, especially when UF* [ultrafiltration] *was 4 liters, I was very weak and tired. I would lie on sofa until nighttime. I could not get up, if I get up, I had giddiness. I did not take my bath, only took little food before I went to sleep.* (Albert)

Besides this physical paradox, the participants also expressed the paradox of emotional response with mixed feelings of thankfulness and appreciation, but also sadness and constant worry.

4.3.2 Mixed feelings of thankfulness and appreciation, but sadness and constant worry

The participants also expressed the paradox of psychological response toward HD. The participants said they felt thankful and appreciative towards the people who designed the HD

machine, the availability of HD treatment to prolong their lives, and the financial assistance in supporting their HD costs:

> *"I am thankful that I can have dialysis and I am still alive."* (Mathew)

> *"Dialysis is useful. Because of dialysis I can live. I am thankful to the dialysis treatment and machine for sustaining my life. If no dialysis machine, I will be upset. I appreciated the people who had created the dialysis machine.* (Putra)

> *"My department is paying for my dialysis expenses and Eprex [medication]. Lucky they help, I really appreciate that."* (Chik)

Besides the feeling of thankfulness and appreciativeness, the participants also expressed their feeling of sadness and constant worry. They described their profound sadness. They were sad and despaired of having this chronic disease that had drastically changed their lives:

> *"I am sad for getting this disease* [ESRD]. *I had never seen a doctor before. I am scared when the doctor told me I had kidney disease. The doctor told me, I needed dialysis, they asked me to be admitted to hospital for dialysis* [stab peritoneal dialysis], *I didn't know anything. I did not know what to do….*" (Chik)

> *"Dialysis had affected my career. It had affected my promotion. Promotion is no more in my dream. I don't want to think about it anymore. If I don't need dialysis, I would aim*

for better position, better pay…//…. When I saw my junior colleagues got promoted, I really felt jealous of them and felt sad that I could not go up to the best position [tearing]

(Mathew)

The participants also highlighted their feeling of constant worry towards HD treatment, malfunction of AVF, prognosis and outcome of their lives:

"I don't use my AVF hand to do my work because I am scare my AVF will fail… //… I paid around RM2000 to have the AVF created. I don't want my AVF to fail. If my AVF fails, I need to pay again for a new AVF." (Faizu)

"I am worried about my children who are still depending on me. They are not working yet. I worry my mum is getting older, I worry who is going to take care of me."

(Aisyah)

Many participants also worry about failure of water supply or electricity power supply because they have experienced several times in the past. Those failures had interrupted their HD treatments. Some participants were worried as they had to go home without HD treatment, or were unable to complete the four hours of HD. Because of incomplete HD treatment, the participants needed to restrict more fluid and diet while waiting for another session of HD two days later. Some participants said they would not consume food and drink because fluid as waste products in their bodies have not been effectively removed. The participants also informed that they would save some money in case they needed to pay extra expenses to receive HD treatment

in another HD center:

> *"When the electricity blackout* [no electricity supply], *I was asked to go home* [without dialysis or not completed 4 hours]. *I was worried because there was still a lot of water in my body. My blood was still dirty. I was forced to control my food and drink more strictly until I received the next dialysis treatment."* (Haron)

> *"When there was no electricity supply or water supply in the dialysis center, I was asked to go home without dialysis. I was very worried as my blood was still dirty, my body fluid had not extracted. When I went home without dialysis, I could only watch other people drinking, but not me….."* (Kelvin)

> *"If no electricity supply in the center, I would not have dialysis for one to two days. I need to control my fluid intake. If I cannot do HD in Nina dialysis center* [current], *I may have to pay for HD in other dialysis center. That is why I need to reserve some money."* (Leo)

Besides that, several participants felt insecure and worried regarding the guarantee of financial assistance and supports from the funding bodies for the HD treatment. They said:

> *"I am worried that my department wouldn't want to continue funding my dialysis expenses. I am worried that they will ask me to stop working. If they don't want to sponsor, then how…."* (Chik)

"I am most worry and concern about my dialysis expenses… //…, I am worried my department will change the policy and discontinue the support for my dialysis treatment. I am worried that if I stop working or retire, I may need to pay dialysis expenses by myself, but I cannot afford to pay…" (Mathew)

4.3.3 Uncertainty and fear

The participants also expressed the feeling of uncertainty and fear towards their disease, condition and prognosis, outcome, life, death, HD treatment, their future, and kidney transplant. Three (3) participants shared their feelings:

"Initially, when I just started dialysis, I always thought how long I would need to have dialysis to make myself healthy. After three months on dialysis, I did not want to think further as I would be upset." (Bella)

"I do not want to have dialysis for the whole life. I cannot stand to have dialysis for so long. I felt restless. I feel the time [4 hours] *is too long. My future is dark* [he has been on dialysis for 26 years*]."* (Edward)

"I do not think any more about my future. I do not know how long I can live."

(Eliana)

Several participants said they are fearful that kidney donation may bring harm to the donor and further affect their family if the donor is from their own family member:

> *"I do not tell my wife about it [kidney transplant]. I also do not want to accept her kidney. If anything happens to her, nobody will take care of our children. Now, I do not dare to think about it [kidney transplant], just continue dialysis."* (Albert)

> *"If I have to ask my family member to donate, I do not want to accept. I am already sick and I do not want others to suffer because of me."* (Doris)

> *"My wife wanted to donate her kidney to me, but I refused. I do not want her to suffer. I also refused to have my son's kidney, as he is still young. I do not want to make him worse. It is enough for me to suffer; I do not want them to suffer also."* (George)

The participants said they were uncertain of their future due to the unknown period of waiting time before they could receive a kidney transplant. They were aware that their chances of receiving a cadaveric kidney transplant, was also slim. The following three (3) participants shared:

> *"I hope somebody can donate a kidney to me but I know many are waiting and there may be little chance for me."* (Faizu)

> *"Initially, when I started dialysis, I thought about it* [commercial kidney transplant]. *...//...Now I do not dare to think of it. It requires a lot of money. Think more*

about it is also useless. I do not know I can have dialysis for how long, I hope I can live until my children grow up [three children; eldest one is 9 years old, second one 6 years old and youngest one is 4 years old]. *At the moment, nothing happens to me is good, the next day I come to dialysis again. I cannot have a transplant… //… just continue dialysis."*

(Albert)

"I had heard many stories about transplant. Dr. May told me, at the moment 16,000 people [dialysis patient] *are waiting, I do not think I can wait. Not need to think about it. …//… My life has to go on with dialysis."* (Brian)

The participants also shared their feeling of uncertainty regarding kidney transplantation. They were worried and fearful of the complications and the restrictions following transplantation. They realized the risk of undergoing kidney transplant surgery as it could be trading one set of problem (dialysis) to another set of problem (transplantation):

"If possible, I want to have a transplant. After the transplant, I can go anywhere. I can work. However, I heard somebody [other dialysis patients in the same dialysis center] *had a bad outcome after transplantation. They died after transplantation* [due to infection]. *After the transplant, I still need to control diet. I want to have a transplant but I am also worried if I do not control my diet well then the kidney may damage again."*

(Kelvin)

"I want a transplant. However, if you give me 20 years later, I do not want it anymore, no point to have transplant again [by the time already 60 years old]. *Transplant is also troublesome. I still need to restrict diet, still needs to take many medications."*

(Brian)

4.4 When life is dependent on haemodialysis

"When life is dependent on haemodialysis" was the second theme identified in this study. This theme consists of three (3) subthemes: "Dialysis dependency", "Restricted life", and "Dialysis related losses".

When life is dependent on haemodialysis it indicated the effects of the HD posed on the life of the participants. The participants highlighted their dependency on HD treatment in a routine and regular basis for the rest of their lives. This chronic illness and HD treatments have also imposed several restrictions on their lives. Participants also experienced multiple losses when their life depended on HD and experienced restrictions that they need to adapt to.

4.4.1 Dialysis Dependency

The participants described the feelings of dialysis dependency because they were not able to live without HD. They need to receive HD treatment three (3) times a week (minimum requirement), every alternate day either every Monday, Wednesday and Friday, or every Tuesday, Thursday and Saturday for the rest of their lives in order to survive.

The participants realized that their need to depend on HD treatment as a life saving measure in a regular interval. They also viewed HD as the best way to help them. They also understood that they cannot live without HD:

> *"I have to receive dialysis treatment. That is the way to live. That is the best way that can help me."* (Helen)

> ***"****Every Tuesday, Thursday, Saturday, I must come to HDU [*Haemodialysis Unit*]. I never miss my dialysis treatment. If I do not have HD, I will have shortness of breath."*
>
> (Aisyah)

> *"I must come for dialysis. If I do not come for dialysis, I will die."* (Florence)

> *"Once I started dialysis, I had never missed it. Dialysis will make me feel better. Dialysis is part of my life. The only thing I need to do now is to go for HD."* (Brian)

Besides that, the participants in this study also acknowledged their dependency on the haemodialysis machine:

> *"Because of availability of the dialysis machine, I can continue to live. If no dialysis machine, no more life. My life is dependent on dialysis machine."* (Albert)

"Haemodialysis machine, I consider it as my life. The machine helps to clean my blood and remove excessive water from my body." (Haron)

*"If there is no HD machine available, I may be gamed over [*die*]."* (Ivan)

Some participants stated that they depended on the healthcare professionals to carry out the HD treatments and HD related procedures, especially those from private and NGO HD centers. A participant also admitted that the attitude of the nurses and their assistance had motivated him to continue the dialysis. They depended on the doctors and nurses to provide them with health information, advice, education and other services to encounter their problems:

"The nurses teach us to do blood pressure checking and weigh ourselves before and after dialysis. The preparation of the dialysis machine, priming, pricking of AVF is done by the nurses." (Bella)

*"Priming, weighing, needling, everything is done by the nurse. I just take off my shoes, watch my AVF hand, the rest the nurse will do…//… If the nurse is friendly, it motivates me to come; I do not feel so heavy hearted [*reluctant to come*]. If the nurse is cruel, I do not feel like to come to the dialysis center, even though I know I really need to come for dialysis but I have no mood to come."* (Putra)

"Initially I did not really know how to control my diet and fluid intake. I had fluid overload problem. I have difficulty in breathing. I cannot lie down to sleep. I need to

sleep in sitting position…..//…Doctor and nurse advised me to restrict fluid intake…..//…Now I have not much problem, I am dialyzing well." (Nick)

The participants were very concerned and talked about the importance of their arterio-venous fistula (AVF) as this is the lifeline for HD treatment. They realized that without AVF, they could not have dialysis, which might be fatal. They explained that when they experienced AVF failure, they needed to have HD through an intra-jugular catheter (IJC) or peritoneal dialysis (PD) to remove toxin, electrolytes, and fluid. These alternative methods of dialysis were more painful and more inconvenient compared to HD through AVF. As such, the participants learned to take care of their fistula, as the creation of a new AVF would further impacts on their financial status:

*"For every HD patient, fistula [*AVF*] is a lifeline for them. Without fistula, they cannot receive HD. Without HD, they may die. Fistula is very important to me also. Without fistula, I cannot have HD….//…. I have to take good care of it. I clean it before the fistula needling. I used "Dettol" to wipe the area around the fistula to avoid infection. I do not use this hand with fistula' to do any heavy work."* (Samuel)

"When AVF failed, I cannot have dialysis. I need to have belly punch [peritoneal dialysis], *or neck prick* [insertion of IJC at the neck]. *It is very painful, very inconvenience."*

(Gina)

"I paid around RM2000 to create the AVF. I do not want my AVF to fail. If my AVF fails, I need to pay again for a new AVF." (Faizu)

A total of 93 % (26 out of 28) of the participants talked about their financial dependency. They were financially dependent on subsidy from the state and federal governments, NGOs, charitable bodies, SOSCO department and/or family member to support their HD treatment, medical expenses, and daily household expenditures:

> *"My brother and sister helped to pay for my dialysis expenses for the first two years. After that, the Ching organization* [charitable body] *sponsored the cost of my dialysis until now."* (Albert)

> *"Initially, I paid for my dialysis treatment for the first 2 to 3 months…//….Now both of my HD and Eprex is under SOCSO sponsorship. I had retired and received "Pencen Ilat" [*daily living disability allowance*] of RM400 every month from SOCSO."* (Haron)

> *"Every month I received RM150 from Social Welfare Department. My sister also gave me money. Anything that I want to buy, she would buy for me. When I have no money, I will ask from her."* (Gina)

The participants highlighted their social support dependency. These supports were from family members, friends and caregivers. Some participants said that they needed their family members or friends to transport to and from dialysis center. Family support was the main reason for them to continue and even accepted the routine HD treatments:

"*I do not know how to drive even though I have a car. In the past my son-in-law used to send and fetch me to and from the dialysis center, but now he cannot make it, so my grandchildren replace him."* (Cindy)

*"My son would send me to HDU and picked me up at night [*every alternate day*] because after dialysis I am tired, I do not dare to drive myself."* (Nick)

"They [doctors] *inserted IJC in my neck, it is painful. After I took panadol* [pain relief], *it was still painful. My parent gave me advice and support. Especially my sister, when my IJC bled, my AVF also bled, she brought me to the hospital at 3 in the morning. She really helped me, encouraged and supported me. Without their support, I would not be able to continue dialysis until now.*" (Chik)

The participants expressed their feelings of dialysis dependency because of the necessity of HD as a life-sustaining treatment regime. They depended on the HD machine for life support and depended on the healthcare professionals to perform dialysis and to solve dialysis related procedures. AVF was their lifeline and in addition, they needed financial and social support for the rest of their lives. All these HD-related dependencies had resulted in several restrictions on the life of the participants.

4.4.2 Restricted Life

"Restricted Life" was a subtheme that revealed how HD treatments had imposed several

restrictions on the participants' lives. These restrictions included lifestyle, diet and fluid intake, time consuming care, daily living activities, social life, financial status, working and travelling.

Some of the participants were aware that they needed to comply with diet and fluid restriction for better health and wellbeing:

> *"I control my diet and fluid because it is good for me. If I take too much fluid, I cannot breathe, especially before I receive the HD treatment."* (Brian)

> *"I tried hard to control my diet and fluid so that I could live longer."* (Citra)

> *"I control my food and drink well. If I had too much fluid in my body, I would had difficulty in breathing, so I must control my fluid intake."* (Haron)

Although some participants were able to control diet and fluid intake well, they were some who expressed their difficulties due to hot weather or they felt thirsty:

> *"I can control my diet and fluid, I do not take too much. I want to eat to live, not live to eat. I cannot eat like last time. I have to follow the doctors' and nurses' advice.*"(Chik)

> *"Diet control is okay, but I had a problem in fluid control. I drink more because the weather is hot. I had tried many ways to control fluid intake. I took ice cub, but when I took more ice cube, my weight would increase more, it is difficult….."* (Daud)

"Controlling my fluid intake is the most difficult thing for me. You know human being usually need water. Only 500 ml fluid is allowed a day is difficult, very, very difficult. My biggest problem is I drink too much. I had tried many ways to control my fluid intake but I still could not control it. I drank more when the weather is hot, or when I felt thirsty. After I have done my housework like cleaning, I drink, after I do cooking, I drink again…." (Putra)

The participants also understood that food and fluid restriction was important to prevent complications such as hypotension, pulmonary oedema and heart failure. However, they complied with food and fluid restriction either per doctor's advice, or because they had experienced the complications. The following are the excerpts:

"*In order to live longer, I must control my diet and fluid intake. I eat less meat. I eat vegetable. I do not eat "santan*" [coconut]. *I cannot take too much fluid. My heart would not function if there is too much fluid in my body. I must follow the doctor's advice."*

(George)

*"My fluid control is very good. I have to control because I am patient on dialysis. Now I do not drink too much. Even the weather is hot, I would still need to control my fluid intake because I do not want to go back to stage one of the HD [*difficulty in breathing*]"*

(Samuel)

Several participants expressed that they were been bounded by the HD schedule in which they had to be hooked up to an HD machine three (3) times a week in an HD center. This fixed

schedule caused restriction, limitation and smooth running of their works. The participants shared their experiences:

> *"HD is really disturbing my work. When I have to visit field estate, I cannot travel continuously for 2 to 3 days. I have to come back to Kuching because I need to receive HD. My work process is not smooth because of the HD. I only can work half day, and spend another half a day in the dialysis center… //… I cannot attend meeting. When they need me to do something, I have to go to the dialysis center…//... My work is really restricted and disrupted."* (Mathew)

> *"Dialysis is really disturbing my working time. My HD schedule is 2, 4, 6 [Tuesday, Thursday, Saturday]. Every time I need to come for dialysis, I have to ask my administrative officer for permission to leave my office."* (Aisyah)

Some participants said that HD treatment also had restricted them from participating in family and social activities. They were not able to bring their children to go anywhere or to manage their children's school activities. After dialysis they would be very tired, thus, they would have to stay at home:

> "*Sometimes, I am not able to follow my family activities."* (Quenton)

> *"I am so fed up of coming to the dialysis center three times a week. I am not able to manage other business… //… unable to handle my children school business, unable to perform housework."* (Eliana)

"I do not have time to go for visiting….//… I cannot follow any function…//… It is difficult for me to bring my child anywhere. After completed the dialysis, I reached home already 3.30 pm. Because of tiredness, I would sleep first until night time and then I just have to stay at home because there is not much time left for the day." (Raymond)

The participants expressed feelings of social isolation and were unable to participate in family and social activities due to fatigue and the need for scheduled HD. The participants talked about the feeling of been left behind due to the time commitments at the HD Centre. They seldom met friends because they could not join them in any heavy sports. They could only attend light activities such as "Kenduri" (party). They refused to attend any social activities on dialysis days:

"Now I seldom meet my friend because I cannot play football with them. If it is just attending "Kenduri" [social party], I still can participate." (Haron)

"When other people invited me to go somewhere on my dialysis day, I refused to follow. I would only follow them after I had received dialysis treatment. I can only bring my son go somewhere on non-dialysis day." (Ivy)

"I felt I had been left behind. I cannot follow them. You know many government departments' activities organized during weekends. I cannot attend as I need to come for dialysis." (Mathew)

When the participants' lives were dependent on haemodialysis, their lifestyles, diet and fluid intake, time, daily living activities, social activities, work and travelling were all being restricted. Therefore, they experienced many losses that could affect their quality of life.

4.4.3 Dialysis Related Losses

The participants in this study also talked about many losses related to their illness and HD treatment. They experienced loss of physical strength (physical loss), loss of employment or earning capability, and loss of freedom (tied up by HD treatment) and loss of future.

The participants explained that after completing HD treatment they were not able to perform daily activities or do their work due to loss of physical strength. Due to extreme tiredness, they could not perform heavy activities:

> *"Now, I cannot do more. I want to, but do not have enough energy."* (Leo)

> *"Now I cannot do heavy activity. I am easily tired even if I climb the staircase. I can do sweeping, but not heavy work. I cannot do grass cutting or planting which I used to do before."* (Haron)

Many participants highlighted that they had loss of employment or earning capability due to the time required for HD treatments, the extreme fatigue, other side effect of dialysis, and not able to find work opportunities. Some participants realized that they might need to stop working, or

change to another profession. Some participants were force to retire even though they were still in working-age:

> *"My employer wanted me to work every day, but I could not* [due to regular HD treatment], *then I stopped working* [as a bus driver]. *After that, I worked in a coffee shop. Not long, they asked me to stop because they were worried something might happen to me…//…I tried 15 times to look for another job but failed. Nobody wants to employ me."*
>
> (Albert)

> *"I stop working after I got sick and started dialysis. I was unable to do my work as my job was heavy duty [*Laboratory machine technician*]…. Even though I want to find another job, nobody wants to employ me because I need to stay in the dialysis center three days in a week."* (George)

> *"Now I cannot work because I get tired easily and I am also worried that my AVF will fail….//…. Now I had retired."* (Haron)

The participants also expressed their loss of freedom because of the fixed HD treatment schedule in a fixed HD center. They lost their freedom to travel due to limited dialysis funding, the fixed location of the HD centers. Whether a HD center is managing by private sector, NGO or Ministry of Health also affected the places that which they would like to visit. They said even though they still could travel, but the need to have HD altered their comfort and limited the places where they wanted to travel. They had to make special arrangements with health care providers if they had to be away from the usual HD center. Besides that, they mentioned that HD

treatment also affected the freedom of their family member:

> *"The most difficult part is lack of freedom. I am unable to go here and there. If I want to travel, I need to find a place that has a dialysis center…//... I never go anywhere, stay in Kuching only. I cannot afford to pay for dialysis in other centers [*her dialysis cost is funded by a charitable body*]."* (Eliana)

> *"I cannot go for Hari Raya's holiday in Betong, it is difficult [*because no private haemodialysis unit*]. If I want to go back, I have to go to Miri to have HD treatment in a private HDU."* (Chik)

> *"I still can travelling….//...But, I only can travel to West Malaysia, Sabah, Sarawak, and also Singapore. When I travelled to Singapore, I need to go to Johor Baharu for my dialysis treatment [*in another HD center under the same NGO*]. That is a bit troublesome. I need to inform the nurses to make special arrangements. I cannot travel to another country that I wish to visit like China and Hong Kong because the dialysis is too expensive there, I cannot afford."* (George)

i

> *"My wife always complains that we cannot go anywhere anymore. My brother invited us to visit him in Canada. He will sponsor us air ticket, but we cannot go." (*Mathew)

Two single female participants shared their feeling of loss of future due to renal failure, and the need to undergo HD treatment for the rest of their lives. They highlighted that because of their

illness they had lost their chances of marriage and having children:

> *"I think to have dialysis for the whole life is just like the end of the story. I have no more future. I cannot get married. I cannot have children. My life only left HD."* (Gina)

> *"People like us have no future. I do not want to have a boyfriend. I do not want to get marry. I am sick. I do not want to make trouble for other people."* (Florence)

The participants experienced multiple losses, both tangible and symbolic, for example, loss of physical strengths, loss of freedom, loss of employment, loss of social life, and the loss of future due to renal disease and HD treatment. In order to encounter all these losses, they had to adapt to new ways of living.

4.5 Adapting into new life with haemodialysis

The third theme, "Adapting into new life with haemodialysis" had three (3) subthemes: (1) adaptation, (2) restructuring family and social life and relationship, and (3) coping. The theme "Adapting into new life with haemodialysis" indicated how the participants adapted and adjusted to the physical, psychological, social, financial and spiritual effects of HD treatment. They had to adapt to new way of lives. They had to restructure their family and social life and relationship, and applied some coping mechanisms to overcome their problems.

4.5.1 Adaptation

The subtheme "adaptation" referred to the adaptation method used by the participants. One (1) participant described a period of denial prior to dialysis, and once HD was initiated and he had benefited from it, he saw the HD as a change that he needs to adapt to. He viewed HD as a normal and routine activity in his life. He elaborated:

> *"Initially, I refuse HD. When doctor told me I had renal failure and needed dialysis, I rejected the dialysis. I did not want to. I thought having dialysis was like going to prison, no way out. Dialysis was a dead sentence for me. I tried to run away from the dialysis. Now HD is a normal and routine activity of my life. I feel okay with HD, not much problem."* (Brian)

All participants had to make adjustments and changes in their lives in order to adapt effectively. As the HD treatment had restricted the participants' time, work and daily activities, some of the participants applied positive adaptation method through proper time management. They scheduled their daily activities based on the HD treatments in order to adapt to the limitations and restrictions caused by HD, or made special arrangements if they needed to receive HD treatment in other HD center:

> *"When I need to visit field estates, I need to do a lot of arrangement. When I travelled to Betong, I cannot receive HD at Betong, I need to arrange my HD in Sarikei. This is because not all the dialysis centers have a dialysis machine for people like me [*hepatitis B surface antigen positive*]."* (Mathew)

"Dialysis is really difficult and wasting my time. My time is limited. As I need to come to the hospital for dialysis, I must divide my time properly according to my dialysis schedule. On the day I need to come for dialysis, I would wake up around 4.30 am. I would finish my housework first. I send my son to nursery before I came to hospital for HD. After I have completed my HD around noon, I would pick him back. On non-dialysis day, I will be a bit more relax. I had more time to do my housework…" (Ivy)

The participants described that they had adjusted themselves physically by reducing the housework or sometimes not doing any work at all to deal with the complications of the disease and the side effects of dialysis such as weakness, headache, vomiting and fatigue. After dialysis, they had to rest for few hours or overnight:

"After dialysis, I am very tired. I really cannot do my work. I cannot do anything. I must lie down and rest, then my energy will return. Even on the non dialysis day, I also do less work because I am easily become tired." (Haron)

"After dialysis, I am tired. I will rest for one to two hours, or sleep a few hours."

(Citra)

"After dialysis, I have to lie down until I feel better. Sometime, if I have a headache, giddiness or vomiting, I need to lie down until night or the next day." (Eliana)

Many participants in this study reported that they took the responsibility to learn how to care for themselves especially the diet and fluid restriction. Some patients also learned how to take vital signs and weighing, while others could do priming, starting and switching off the HD procedures. They also needed to adapt themselves through learning and compliance to the diet and fluid restriction, medication and HD treatment to avoid complication of illness and dialysis. Only one (1) participant learned to do needle insertion, the rest were afraid of needles and preferred nurses to perform the canulation:

> *"In the first 1 to 2 year, I really suffered, very difficult to adjust myself. I always felt thirsty. I still wanted to drink more. This had made me having difficulty in breathing. I took 2 to 3 years to adjust myself to drink less. Last time, I used to take a glass of water during mealtime, but now I need to control my intake of fluid. I learn not to drink one glass of water again. I also control my diet by eating less. I take calcium tablets* [calcium carbonate] *together with my meal as ordered."* (George)

> *"I learn to check my B/P* [blood pressure], *weighing. I also know how to do priming… I start HD…//…I can turn it off myself, only I "tidak berani cucuk sendiri" (I am not brave enough to do the canulation). I prefer the nurse to do it."* (Gina)

The vascular access devices for HD such as AVF or IJC were problematic, and caused stress to the participants. When they had bleeding at the AVF and IJC sites, they had to visit the emergency department. Every time when they had malfunction of AVF, they needed to have a re-creation of the AVF. When they developed infection at AVF or IJC site, they would have chills

and rigor. This led to frequent creation of AVF and insertion of the IJC. While waiting for the new AVF to be ready for use, they received HD through IJC for a year rather than the recommended period of two (2) to four (4) weeks. They felt inconvenienced in performing their daily living activities. They were very stressful with a catheter at their necks. They had trouble in taking a bath. Thus, they had learnt some measures to adapt to these difficulties, such as washing their hair in a pail, or shampooing their hair in the saloon. Besides having to deal with the pain and bleeding at IJC exit site, the participants were also fearful of the IJC became dislodged. All these fear, worry and stress had caused the participants' to have troubled sleep. They said:

"*My IJC and AVF had a lot of problems. When the IJC site bled, and my AVF site also bled* [new creation*], I went to the emergency department, they* [health care workers] *helped to stop the bleeding. On the second night, I went to emergency department again as my AVF site still bled. They told me my AVF was not good [not functioning] …//…. I had three AVF creations. My first and second AVF was not functioning well. There was no more bleeding from my third AVF. But, while waiting for my third AVF to be ready for use, I used IJC for almost a year."* (Chik)

"I had dialysis for two months through IJC. I really suffered, very difficult to take a bath. It was painful and sometime bleeding [from the exit site of the catheter]. *I was scared and worried that the catheter would dislodge. I could not sleep well."* (Doris)

"When my AVF failed, I needed to use IJC for dialysis. I do not like to use IJC. It is very difficult to take a bath. I need to take care of it. It cannot get wet. I bathed half of my

body [lower part] *only. The upper part of my body, I just wiped with a cloth. I washed my hair in the pail."* (Eliana)

"I have suffered enough with the AVF problem. My first AVF was not functioning. My left hand had two times AVF creation. My right hand had three times. I had three times IJC insertion and one time femoral catheter insertion [due to bleeding and infection of AVF]." (Edward)

"IJC is also very difficult, really suffer. I cannot turn my neck. I had fever, chills and rigor while on IJC." (Ivan)

The participants in this study have highlighted pain caused by insertion of needles at AVF. A young male participant described the pain caused by the direct application of needles into the body can be stressful until he was scared to turn up for HD treatment. He explained that he had to overcome the pain and accepted needling was necessary in HD in order to remove waste products and body fluid and to prolong his life. Another male patient also shared the same fear and hoping for something similar to intravenous brannula that could be connect to AVF permanently to avoid pain:

"I am scared of needling [around fistula]. I am scared of pain. When I think of needling, I am scared to go to haemodialysis unit. But then, I think, if there is no needling, I cannot have dialysis. If no HD, I am scared the toxin will accumulate in my blood, I will not be healthy, I will have difficulty in breathing. I think the dialysis would help to sustain my

life, the needle pain is just a few second, so I have to tolerate it. Now I have already gotten used to the level of pain caused by the needling." (Kelvin)

"Insertion of needles at AVF is really painful. I am scared. I hope they can put something in my AVF arm, something like intravenous brannula to be permanent there and can be connected to when needed." (Ivan)

The participants in this study described how they sought for financial assistance to pay for the cost of HD treatment, AVF creation, medication expenses, daily expenses and the loss of employment. Some participants explained that their family members needed to do extra jobs and borrowed money from employers. Besides that, they also sought financial assistance from federal and state government, SOCSO or charity bodies to pay for these costs. Some participants received assistance from family and friend for daily living expenses. However, participants realized and understood that their family members and friends could not help them much as they had their own commitments:

"When I just had this disease [kidney failure], *I did not have enough money for dialysis expenses. My husband* [taxi driver] *needed to find more money for my dialysis expenses. He needed to do extra job to get more money."* (Doris)

"My father and my boss helped me to pay for the cost of dialysis and AVF creation. My father borrowed money from his boss." (Kelvin)

*"My HD and Eprex injection were under the SOSCO. I received RM400 per month [*Pencen Ilat*] but this is not enough for my car petrol. I have to manage my money well. Sometimes my friends would support me a bit. My family members also help but cannot do much as they have their own commitments."* (Ivan)

"Although I do not need to pay for dialysis [under charitable body], *I need to spend money on car petrol* [from Serian to Kuching] *and other expenses. I asked help from the Social Welfare department. I received RM300 per month. RM300 is not enough. My siblings [six of them] would give me money for my daily expenses."* (Jaya)

Many participants in this study highlighted the high dialysis cost was a financial burden that was insurmountable at times. When there was no HD slot available at government hospital, they needed to receive HD treatment in an NGO or private HD Centre in order to prolong their lives. Before they received any financial assistance, they adjusted themselves by moving from one HD center to another where the HD cost was lower to reduce their financial burden:

*"After I had six sessions of dialysis in a government hospital [*no dialysis slot*], I continued my dialysis in Kawan Dialysis Centre* [private dialysis center, one session of dialysis is RM160]. *I had my dialysis there for two months, then I moved to Nina Dialysis Centre* [NGO dialysis center, dialysis cost is RM110 per session]. *My husband still needed to find more money."* (Doris)

"I started my HD in Tara Dialysis Centre [private]. *...//...After two weeks, I switched to the Rema Dialysis Centre* [a private dialysis center but the dialysis cost is lesser compared to Tara Dialysis Center] *for two weeks also. When the Nina dialysis center* [NGO dialysis center] *has accepted my dialysis application, I moved again and had dialysis here until now. Now the SOCSO had provided funding for my dialysis and Eprex injection."*

(Leo)

Thus, the costs of HD treatment were a major source of stress and concern among the participants. However, the participants claimed that they felt less stress and worry after they had received some financial assistance and support from government, SOCSO, community welfare department or charitable bodies:

"At that time, my husband needed to find more money. I was very worried, really "big head" until SOSCO supported my dialysis expenses" (Doris)

"My dialysis is funded by Nata Charitable body. The social welfare department also gave me RM100 per month. The Sarah Church gave me some money every month. It is enough for my daily expenses." (Eliana)

"I have experienced the condition that when I cannot pay, I could not receive dialysis treatment ever though the staff here had already prime the blood line….//... However, I am quite okay now. Since year 2008, my dialysis has been funded by SOCSO included Eprex injection. I also received "Pencen Ilat"; RM400 every month." (Helen)

Besides positive adaptation, some participants use negative adaptation by skipping one (1) session of the HD treatment in a week due to transport problem. Another participant explained that when he needed to attend courses more than three (3) days, he would skip one (1) session of dialysis treatment or he would ask the HD staff to rearrange his HD schedule:

> "*My experience of dialysis really troublesome/worse…. //… Last time [in year 2000], I did not have a place to stay [in Kuching]….//… After dialysis, I went home [in Bau] by bus. The bus would stop at the junction and then I had to walk for 45 minutes to reach my house. I always felt reluctant to come to Kuching. I would skip one session of dialysis in a week, usually it would be Thursday."* (Florence)

> *"If I need to attend a course for three days such as Wednesday, Thursday and Friday, I would skip my HD on Thursday. If only one day course, for example, Monday, I can accept. If the course last for more than one day, I would not accept, especially Tuesday because the duration for not receiving dialysis is too long*. [If the last session of HD is on Saturday, he will not receive HD from Sunday until next Thursday]. *I may need to rearrange the HD schedule with the nurse if I want to follow any course."*
>
> (Raymond)

All of the participants in this study had actively made adjustment and changes physically, psychologically, socially, emotionally and financially in order to adapt themselves effectively into their new lives with HD. In addition, the participants needed to restructure their lives and

relationships in order to adapt themselves to all these changes.

4.5.2 Restructuring family and social life and relationship

This subtheme, "restructuring family and social life and relationship" reflected the impact of HD on the family. The participants in this study explained that they had to restructure their family roles and relationships in order to cope with the needs of HD. They elaborated that when a family member had a serious illness such as ESRD, the other family members need to make major changes in their usual roles and responsibilities in order to accommodate the illness' demands.

The participants described the changes in their family roles and responsibilities. They were unable to fulfill their roles as a mother or father due to regular dialysis treatment and physical fatigue. The other family members such as participants' own mother and daughter needed to take over the participants' family roles. Their children had to learn to be more independent and cared for themselves. The female participants said that their sons, daughters or husbands needed to help in cooking, cleaning and other housework because they were unable to perform the tasks due to giddiness and tiredness after haemodialysis:

> ***"****Since I started dialysis, my mother is helping me to take care of my children and myself. After dialysis, I would be tired so I could not do cooking. I can only do the cooking on non-dialysis day. My eldest daughter is doing the cooking and cleaning, the other children have to learn to care for themselves."* (Aisyah)

"After dialysis, I felt giddy and tired. I would sleep until evening. My son will do cooking, cleaning and other housework. My husband will help also. Last time I can do housework, now I cannot do. Anyway, I can do housework on non-dialysis day." (Bella)

Children are highly valued in a family. When the children grow up, they are expected to take care of their parents in their old age or in ill health. However, an adult participant talked about dialysis and physical fatigue problems which made him unable to care for his parents but instead his parents were the ones taking care of him**:**

"I stay with my parent, by right I should be responsible for taking care of my parent in their old age, but now my parent [age more than 60] *are taking care of me* [age 41], *my father sent me to dialysis unit, and pick me home after dialysis. My mother cooked for me."* (Brian)

Other than that, this study also found that the traditional roles of men and women in the family structure were changing. The man is usually the head of the household and decision maker, but a male participant described his role had changed. This participant's wife had to take over his role to manage their vegetable farm. Their family income depended on his wife. Another male participant shared similar changes, his wife went to work and he became a homemaker. He took on the female gender roles such as cooking, sweeping the floor, washing clothes, sent and fetched children to and from the school. They said:

"Before I started dialysis, my wife was a housewife. Now my wife could arrange the things in my house. She is also managing our vegetable farm. She instructed the workers. I am not the head of the family any more. She is the head of my family. My family income depended on her. She needs to support our younger son who is still studying in university."

(Oscar)

***"**Now my wife is working. I am taking care of my children. I send my wife to work and pick her back from work. I do cooking, sweeping, mopping, washing the clothes and other housework after I have enough rest. I become a homemaker. I also send my son to school and then fetch him back."* (Haron)

Some participants explained that the dependency and restrictions of HD therapy had prevented them from performing many activities that they could do in the past, and forced them to restructure their work and employment. They had changed job or profession in order to adjust to the need of HD treatment. For example, a participant decided to stop his timber export business, and changed to manage a share trading business because it was difficult for him to visit other countries or entertain customers. Another participant stopped working as a bus driver, changed to become a farmer and part time housing renovation worker. Other participants said they had to stop working because of inability to lift heavy furniture or equipment or unable to work every day. The participants also explained how they arranged their work on dialysis day and non-dialysis day:

"I have already stopped working [as furniture carpenter]. *I cannot use my AVF hand to leave heavy objects. I am scared that my AVF will not function. I can do light duty only.*

Even on the non-dialysis day, I also do less work because I am easily tired. After I stopped working, I operated my own saloon, but I could not stand for long period, then I closed it [due to tiredness]. *Now I am retired* [38 years old]." (Haron)

"As I was not able to work every day, I stopped working [as a bus driver]. *After that I worked in a café for a few months, then they* [employer] *ask me to stop* [because scared of something might happen to him]*...//...Now I do my own vegetable farming, sometimes I help my friend in housing renovation."* (Albert)

"After I started the dialysis, my life is affected. I had to make changes. It was more difficult for me to continue my business. I could not visit other countries with my customers. My customers came to meet me but I could not entertain them. About one year on dialysis, I decided to stop my business. I have to close down my timber export. Now I manage a share trading business." (Quenton)

"On dialysis days, I go to work in the morning until 1pm. Then I came to the dialysis center for dialysis. On the non-dialysis day, I work the whole day. Before I get sick, I would be in the field for the whole day, but now I only do light duty in the office most of the time, only sometime I go to the field." (Mathew)

The participants stated that they had to make new arrangements in their social activities and lifestyle. A participant shared that he could not be involved in heavy sport activities. He only selected light activities based on his stamina. This participant also explained that he could not

attend any courses related to his job as he like, but rather he had to select those courses that fell on the non-dialysis day. Another participant explained that it was difficult for him to go anywhere due to his HD. Whenever he was not having HD in Kuching, he would watch television programme at home or visited his friends nearby. His physical fatigue had made it difficult for him to do planting or gardening as before. Some participants mentioned that sometimes the family member had to re-reschedule their dinnertime due to their dialysis:

> *"Before I fall sick, I could do anything. I could play football. ...//...I could go anywhere. As I need dialysis, I could not do more now.../...Last time, I was a football player, but now I become a supporter. Actually, I like camping, playing in the river but because of the need for dialysis and I am easily tired, not enough energy, and less stamina, I changed to light sport. I play snooker."* (Raymond)

> "*My children need to adjust our family dinnertime to suit my dialysis schedule. They will ask me first before they make any arrangement."* (Quenton)

> *The dialysis had made it difficult for me to go anywhere. I cannot go anywhere. If I do not need to come to the dialysis center in Kuching, I just stay at home watching television programmes. I cannot do planting or gardening because I am easily tired. Sometimes I only visit my friends who are nearby in Serian."* (Jaya)

The participants also explained that they had to construct relationships with other HD patients, nurses and doctors. They revealed that as they needed to receive HD three (3) times a week on

every alternate day, they spent more time with the other HD patients and HD staffs compared with their own family members and relatives. They viewed the other HD patients as their teachers, friends or colleagues who had a lot of experience in managing the HD treatment. When they encountered any problem, they always approached the other patients who were on the same shift of HD with them. They helped each other and provided support for each other. The participants shared information and learned from each other. Besides that, the majority of the participants informed that they developed new, supportive, close and good relationships with nurses as well as doctors in the HD centers. They viewed doctors and nurses as their family members and friends as well. This is proven in Faizu, Gina, Kelvin and Samuel' statement:

> *"1,3,5 (Monday, Wednesday, Friday), I need to come for dialysis. 2,4,6 (Tuesday, Thursday, Saturday), I will stay at home. I do not have other friend. The dialysis patients who are on the same shift with me are my friends."* (Gina)

> *"When I had a problem, I always approached dialysis patients who had a lot of experience in managing the dialysis treatment. They are my teachers, friends or colleagues. I am their student."* (Kelvin)

> *"I learn from them [other dialysis patients]. We shared informations. We learned from each other. I got support from them. When I have a problem, I will see them."*
>
> *(*Samuel)

"*The patients who are on the same shift with me also have the same problem [*renal failure*] like me. I get advice from them, and also doctors and nurses. We are just like one family."*

(Faizu)

Some participants viewed their HD Centers as their second home or another working place:

"Here [HD Unit] *is just like my home, second home. The staff* [nurses] *here are like my family members."* (Bella)

*"Coming for HD is like coming to work. 8 am go to work, talks to friends here [*other dialysis patients*], off for lunch, finish HD, go back, sleep. It is just like having normal life every alternate day, same routine.* (Brian)

All of the participants appeared to be actively adapted into their new life when depending on HD. They were restructuring their life and constructing relationship with other HD patients, nurses and doctors. They also used various coping mechanisms in order to cope with the effects of HD treatment.

4.5.3 Coping

The subtheme for "coping" included various coping strategies used by the participants to cope with HD treatment. The participants tried to be positive, acquire acceptance of their condition, used peer learning and support from other dialysis patients, sought help from support system such

as family, health care providers, friends and religious bodies, and living in hope.

Many participants adopted positive attitude as their coping mechanism. These positive attitudes included positive thinking and comparing themselves with other patients who were more seriously ill such as cancer patients. The participants said they did not want to think more to avoid stress after been informed by a doctor that they had to undergo HD for the rest of their lives. They only wanted to be healthy. They tried to think positively, be happy and forget that they were sick:

> *"Doctor told me I had to do HD for my whole life. I do not want to think more. If I think more, I will be stress. I think of my health only."* (Faizu)

> *"I do not want to think that I am sick. If I am stress, if I have negative thinking, I will die faster. Think positive. Be happy. Forget I am sick."* (Gina)

> *"I think I am better than other people who have cancer. They cannot eat, but I still can eat."* (Kelvin)

Some participants revealed that they coped with HD by being actively involved in learning about how to care for their AVF and fluid extraction during HD. They changed their mindset, faced the reality positively and solved their problem. They said HD treatment was only taking four (4) hours, three (3) times a week. They still had plenty of time. They still could do many things:

"…. I learn how to take care of my fistula…//…I learned how not to extract too much fluid from my body." (Gina)

"Everything depends on your mindset. Do not worry too much. Worry cannot help. The best way is to face the reality. If I have a problem, just face it, solve it….//…HD only takes four hours, three times a week. We still have plenty of time. I still can do many things…//…You must have positive thinking. If your mindset said you need to change, then just change." (Quenton)

Several participants informed that they had accepted their disease, HD treatment and restrictions while living with HD. The participants were forced to accept HD due to the life threatening situations such as difficulty in breathing. They had no choice but to accept HD for survival. They also realized that if they did not want to accept HD, they would suffer, or burdened their family:

"I accept it [HD]. *I took almost a year to accept it because there was no other way. At that time* [when he cannot breath normally], *no other choice, either you die or you go for HD, so just try HD, or if not, just wait to die.* (Brian)

"*Dialysis is to prolong my life, I must accept it. Even if I cry every day until I become blind also I still need to do dialysis."* (Putra)

*"I cannot change this situation [*Haemodialysis for whole life*]. HD can prolong my life,*

so I must accept it. If I do not want to accept it, I will suffer. I will burden my family also."

(Doris)

Peer learning and support was another coping strategy used by the participants. The participants actively learned about their illness, diet and fluid restrictions and HD treatment from other HD patients. They preferred to receive advice and support from the other HD patients who had the same experiences:

"The long standing dialysis patients always gave me advice and support…//… When I approached them, they told me that they also had gone through the same problem. They would teach me how to solve it. They helped me a lot. They taught me how to care for myself. They also taught me about diet." (Kelvin)

"The other HD patients are my friend. They will help me. Anything that I am not sure, I will ask them. Sometime I do not have enough medication; I would borrow from them first. After I collect mine, I would return." (Leo)

"After I had started dialysis treatment, I was very much stressed. My life was upside down…//…I approached the other patients. …//…I told them I felt like dying. They advised me not to think like that, but think positively…. //… I also find people to talk through online. I can chat with patients in US [United States], Australia and Germany online…//…When a patient talk to another patient, it is easier as they have the same problem, instead of doctors or nurses who will tell you not to do this, not to do that. The

information about the patient provided is more reliable. What the doctors and nurses tell us is just theory." (Samuel)

The family was the most important source of social support for the participants. All of the participants said that they received help and social support from their family members. The family was a motivator and supporter for them to cope with the HD treatments. These family members transported them to and from the HD center and helped in solving their financial difficulties. A male participant told me that his wife had to be involved in his care. She learned to prepare suitable food for him. His wife and children also changed their menu in order to help him to cope with the dietary restriction:

"My mother always advised me to listen to doctor's instruction. My aunty treats me as her child…..//…My cousin treats me like her sister. She gives me advice, gives me money. She always sent me to the dialysis center and brought me home. I am very lucky to have them." (Gina)

"Sometimes I drive myself, but most of the time my mother sends me to the dialysis center and picks me home. She also sends me to the hospital for follow up." (Kelvin)

*"Luckily I have my husband to accompany me so that I can continue until now. My family members also give me financial support, especially my brother; he helped me to pay for my AVF creation [*RM2000.00*]."* (Helen)

"My wife needs to change the food preparation. She learned how to breach potassium from the food. She learned what type of food I should avoid and reduced salt in the food. Whatever I eat, my wife and my children also follow." (Samuel)

Many participants mentioned that health care professionals especially doctors and nursing staffs were the sources of support for them. Health care professionals provided them with advice, guidance and health information to help them to cope with illness and HD treatment more effectively:

"The nurse always gave me advice, guidance and provided me information on how to control my diet and fluid. Even though some of the patients may not want to listen, she still continues to give." (Ivan)

"The nurses talked about everything here. The nurse would explain what we should do, what we should not do. They talked about health issues and diet, blood test results and medication. They provided firsthand information…//… The doctor advised me not to extract too much fluid or not below my dry weight." (Samuel)

Some participants expressed that the social and financial supports from their friends have encouraged and motivated them to continue HD treatment:

"Sometimes if I am not feeling well, I cannot drive. My friend would send me to the dialysis center. Sometime after dialysis, I had giddiness; my friend would bring me home." (Ivan)

"My friend always brought me out. My old classmates gave me some financial support. They gave me encouragement. They asked me not to give up. Because of them, I can continue until now." (Helen)

The participants also learned to cope with the psychological effects of the HD through prayer, faith in God, and trust in God. A female participant shared how she had adjusted her sadness, dislikes of HD treatment, and stress towards her chronic disease and dialysis dependency by blaming the world for not being fair to her. Another female participant confided that she adapted to the stress through religious support by reading religious books, visiting the temple and listening to religious songs. An older male participant shared how he adapted and coped with his dialysis life through prayer and receiving counseling from the church. He believed that God had helped him to cope better with HD compared to the other younger HD patients. Some participants prayed to God for recovery and a better outcome of the disease according to their own religion. Acceptance of their illness and condition was relevant to the perceptions of their religious faith:

"I felt so sad that I needed to have dialysis for the whole life. I fall sick [kidney disease] *since I was small. I do not know the cause of my disease* [ESRD]. *I think this world is not fair. People who did not take good care of their health also did not get sick."*

(Eliana)

"Initially I was stressed when I thought of why only I had this kidney disease while nobody in my family developed renal failure. I thought of taking a sleeping pill then just

died during sleep. When I was stressed, I would read Buddhist book, or visit the temple, or listen to religious song, then I feel more comfortable and less stress." (Helen)

"When I had kidney disease, I prayed to God for recovery. I went to the church for counseling. Before I started dialysis and even now, I still go to church every weekend. ...//... I believe God will help us if we believe in Him. Now I think God is helping me. I have not much problem with dialysis .... //... I saw other patients had many problems and not healthy after commencing the HD, just like Peter who is 49 years old, much younger than me, also has many problems with dialysis...//...We absolutely need to seek help from God." (Oscar)

"Initially I could not accept the reality, but now I have accepted it. I pray to God. May be God has His reason. This may be destined. Life must go on. If I am disappointed now I can jump [commit suicide]. *This is not God's will. My life depends on God. If God does not want to give me long life, it is up to Him."* (Gina)

"I have kidney disease since 10 years ago...//... I prayed to God to heal me or delay the progression of renal failure because at that time my children were still small. My pastor, my family members and church members always prayed together for my health. When I started dialysis, my children had grown up and started working. That was why I did not have much burden. I think God is really helping me." (Leo)

The participants in this study used various coping mechanisms to cope with their chronic disease,

HD treatment and HD related problems. They were being positive, accepted their condition, engaged in peer learning and received support from other patients. They also looked for help from their support systems such as family, health care providers, friends and religious bodies to cope and manage their lives. The participants have developed hope and looked forward to the future when HD had prolonged their lives.

4.6 A sense of hope in the unknown future

The final theme identified was "A sense of hope in the unknown future". This theme consisted of four (4) subthemes - "Hope to restore good health, attain pre dialysis status and live healthily", "Hope for kidney transplantation", "Hope for employment", and "Hope for freedom to live".

A participant mentioned that after he received HD treatments, he accepted HD and viewed the HD unit as a place that could give him hope. Another participant had hoped to win a lottery so that he could have kidney transplant:

> *"I think everything that I experienced is fate. I have to accept the fact. My wife gave me advice and support from the beginning. She told me that what God has given to us, we just have to accept it. All that she faced, she had to bear with it. As a Muslim, I always pray for recovery from all my diseases* [also diagnosed with diabetes mellitus]. *After I had prayed, I felt more at peace. This made me a bit more patience and less upset. I accepted dialysis because I need it. I think in here* [dialysis unit], *there is hope."*
>
> (Putra)

"…//…. When I have money, I buy jackpot [lottery]. *If I win money, I want to have a kidney transplant. Nothing can make me feel happier until I get kidney transplantation and have a new life."* (Edward)

After initiation of HD, the participants' physical and emotional health improved. When the HD prolonged the participants' lives, they had happiness and hope. They developed a sense of hope and looked forward to the future. They talked about the hope to restore good health, attain pre dialysis status and live healthily, hope for kidney transplant, hope for employment and hope for freedom to live.

4.6.1 Hope to restore good health, attain pre dialysis status and live healthily

The participants revealed a desire to restore good health, attain pre dialysis status and live as healthy as they did prior to HD treatments:

"In my mind, I always think about how to be healthy again. If possible, I hope I can recover, then, I do not need dialysis anymore." (Haron)

"I hope God can free me from dialysis and give me health." (Oscar)

"If possible, I do not want to do dialysis. I want to be healthy again". (Jaya)

4.6.2 Hope for a kidney transplant

Some participants highlighted their hopes for the possibility of a kidney transplant. The participants talked about looking forward to future kidney transplantation. They hoped that after kidney transplantation, they would be free from dialysis, their life would be more convenient, less restrictions, have better quality of life, free to travel and they would have a brighter future:

> *"I want to have a transplant* [cadaveric] *because transplant will make my life more convenient."* (Doris)

> *"I hope after I have a kidney transplant, I do not need dialysis anymore. I can find a job and earn more money."* (Albert)

> *"If somebody can donate a kidney to me, I am willing to receive it anytime. After I have transplantation, my life will change. I will not need dialysis anymore. My life will go back to normal, even though not 100%. My lifestyle will be less restricted. If I do not need dialysis, I can travel to any place that I want. I may not be able to eat as I like but at least not really limited. My future will become brighter."* (Mathew)

4.6.3 Hope for employment

Several participants also hoped for employment. They expressed their wishes to get a permanent job. They hoped that the government would provide some light jobs for people living with HD.

They believed that getting a job could change their financial status and provide them a better life:

> *"People like us three days working, another three days cannot work, nobody wants to employ us. I still want to work* [already receiving "Pencen Ilat"]*….//...I think government should do something. The government should offer jobs for HD patients, for example, some light jobs which can be completed within one day."* (Ivan)

> *"If I can get a job, I still want to work. If I can earn extra RM400 to RM500 every month, it will be better.* (Leo)

> *"Now my wife is supporting our family. I had retired* [he is receiving RM400 per month from SOCSO department]. *If I can work, I still want to work. If I can return to work, I can help my wife and I can support my household expenses. I can change the condition in my house. I saw other people* [neighbor, friends] *having a happy and luxurious life, I want luxurious life also."* (Haron)

4.6.4 Hope for freedom to live

Some participants talked about a sense of freedom after a successful kidney transplant. They hoped they could go anywhere after a kidney transplant. They were looking forward to a time when they would experience freedom again. They also hoped somebody could design a more advanced HD machine that is portable, wearable, and smaller like a computer laptop bag, then, they can carry the HD machine everywhere with them. They can travel freely to anywhere, at any

time without any restriction and limitation:

> *"If possible I want to have a transplant so that I am free to travel. When I still continued with dialysis, I hope someone can design a portable dialysis machine that is small and handy like this* [pointed to a computer laptop bag in front of him]. *Now, I am forced to follow the dialysis machine. I hope I can carry the machine on my body then I can go anywhere that I like."* (Kelvin)

> *"When I retire, I hope I am still healthy with dialysis. I want to bring my wife for travelling ...//... I hope I can bring my wife to Canada after I retire. If I still do not receive a kidney transplant, I hope there will be a portable dialysis machine which can travel with me."* (Mathew)

> *"The current dialysis machine is too big. I hope the machine can be smaller. I hope a scientist can design a portable dialysis machine, can bring together with me, can follow me everywhere. Who knows, last time the computer was big, now we have laptop* [pointed to the laptop in front of her] *last time our mobile phone was big, now the mobile phone has become smaller and smaller."* (Aisyah)

4.7 Summary

Twenty-eight adult patients shared their experiences of living with lifelong HD treatment. They shared that they had benefited and felt better after the initiation of HD treatments. However, they

also suffered from the negative effects associated with HD. They revealed that their lives were dependent on HD treatment, HD machine, health care providers, AVF, financial and social support. They lived a restricted life. They had encountered HD related losses. They described how they adapted to HD treatment physically, psychologically, socially, emotionally, financially and spiritually by applying various positive and negative coping mechanisms. Although participants had accepted HD as a necessary treatment to sustain their lives, they did not want to live with it for the rest of their lives. They were appreciative and thankful with HD treatment but at the same time, they were overwhelmed with negative emotions such as sadness, stress, worry, uncertainty and fear. Nevertheless, these patients had developed a sense of hope to restore good health, attain pre-dialysis status and live a healthy life. They also hope for kidney transplant, return to work, and had freedom to live. The next chapter would discuss the study findings in detail.

CHAPTER 5

DISCUSSIONS

5.0 Introduction

This chapter discusses the four (4) major themes: “Living with the paradox”, “When life is dependent on haemodialysis”, “Adapting into new life with haemodialysis”, and “A sense of hope in the unknown future” found in this study. The findings are discussed in relation to findings of past studies cited in literature review. A summary concludes this chapter.

5.1 Living with the paradox

The participants were found living with the paradox. A paradox is an argument that produces an inconsistency, typically within logic or common sense. The "paradox" refers to the irony or contradiction in receiving HD by the participants. This is further explained in the subthemes.

5.1.1 HD was beneficial but problematic

The participant experienced the benefits and adverse effects brought by HD. HD treatment helped patients to feel better, improved their appetite, increase ability to walk and lived longer. It improved their physical well-being with less ESRD symptoms such as breathlessness, nausea, vomiting, and loss of appetite. This finding is consistent with that of Sadala and Lorencon (2006)

in Brazil who highlighted the improvement of renal failure symptoms and possibility of recovering some well-being. However, the participants also reported that they experienced adverse effects of HD such as hypotension, leg cramps, abdominal cramps, headache and fatigue. This finding is similar to the results reported by Polaschek (2003) in New Zealand who found patients talking about symptoms related to HD treatments such as vomiting, headache, leg cramps, lack of physical strength or fatigue and other difficulties with extreme tiredness.

Among all physical impacts related to HD treatments, almost all the participants experienced fatigue. Fatigue is a very inconvenient symptom because it caused participants to lose physical strength and energy to do anything especially on their dialysis day. They needed help because fatigue reduced functional capacity and affected their ability to carry out everyday chores, such as managing their personal hygiene; cooking; cleaning and other daily living activities. The post dialysis fatigue often contributed to the inability to participate in daily living activities were consistent with findings reported in other studies (Kaba *et al*., 2007; Lee *et al*., 2007; Polner *et al.*, 2011). The participants were unable to demonstrate effective role performance, and thus experienced role strain and role stress, which was similar to the findings of Lee *et al*. (2007) in Taiwan. Lack of energy due to fatigue could lead to limitations in vitality, poor physical functioning and physical role limitations (Kaba *et al*., 2007). This fatigue affected participants' working lives and participation in normal social events that made them feel their lives were out of control. On the one hand, participants felt HD was beneficial but as the same time, they found it problematic. The physical effects of HD treatment were considered significant and created problems to participants' lives because those effects were continuous and persistent which necessitated them to adapt to these changes. Polner *et al*. (2011) commented that these

limitations had significantly increased the risk of poor outcome in patients. They also highlighted difficulties in performing basic activities of daily living as a result of fatigue would lead to depression which in turn could further increase functional disability and non-adherence to diet and medication. Functional status or the ability to perform activities, such as walking, bathing, dressing, getting out of bed, and using the toilet in HD patients is a key aspect of quality of life, a strong predictor of survival, and a determinant of care giving needs (Carey, Walter, Lindquist & Convisky, 2004, Cited in Theofilou, Synodinou, & Pnagiotaki, 2013). A chronic disease such ESRD cannot be cured, thus, the degree to which a patient's physical inability is effectively managed would help to improve the overall quality of the life of the patients.

5.1.2 Mixed emotional feeling

Besides the physical paradox, some emotional paradoxes were also identified in this study. The feeling of appreciation and thankfulness towards the availability of financial assistance, HD machine and HD treatment to sustain life was identified among most of the participants. The feeling of appreciation and thankfulness is consistent with the finding reported by Calvey and Mee (2011). They found patients on HD developed a greater appreciation of life and the second chance gifted by HD treatment while they realized that life was fragile and could be lost easily. The participants in this study had these feelings as they realized that they might die if they did not receive HD, or do not have an HD machine to carry out HD treatment, or did not have funding body to provide financial assistance to support their HD treatment and other costs. However, the feeling of thankfulness and appreciations were overwhelmed by the feeling of stress, worry, uncertainty, fear, and sadness when the participants had to cope with many changes, disruptions,

restrictions and adversities. All these adversities highlighted by participants, for example, HD treatments; diet and fluid restriction; vascular access related pain and problems**;** the continuity of financial assistance; failure of electrical power and water supply; prognosis, outcome, future and kidney transplant were identified as fundamental source of stress.

The participants were stress by regular and time-consuming HD treatment. This finding was similar to Shih and Honey (2011) in Northland who reported that their patients were stress as HD required lifestyle changes due to time-consuming HD treatment and the need to travel long distances to have HD. All these affected their quality of life. Besides that, the need for diet and fluid control to avoid complications of the ESRD and for better health and wellbeing also caused stress. This finding was similar to the finding reported by Corrigan (2011) who found food and fluid restrictions as the patients' biggest problems and difficulties as well as a challenge to follow the treatment protocol. The participants in this study were also stress by vascular access related problems such as having a catheter on their necks (placement of IJC), pain, inconvenience, and bleeding from the exit site of the catheter. They were worried and fearful of dislodgement of their IJC. All of these fear, worry and stress contributed to sleep disturbance that was in contrast with the study finding reported by Lee *et al*. (2007) in Taiwan. Lee *et al.* (2007) reported insomnia, difficulty falling asleep and frequent waking from sleep occurs due the disease, HD treatment, and medications.

The participants were worried about the continuity of their financial assistance or support from the funding bodies. These worries were dued to the fact that they were totally dependent on the funding bodies to support the cost of HD treatment, AVF creation cost, medication and daily

household expenses. The participants were worried about the possibility of continued support from their employers even when they were no longer employed. This study's finding is in contrast to the study done by Shih and Honey (2011). Shih and Honey (2011)'s participants received private insurance or state programme, or federal health insurance plans to pay for much of their HD cost. These patients did not report any stress related to financial support most probably because their financial aids were guaranteed. In my current nephrology practice, nurses and doctors are actively helping patients to seek financial assistance from HD funding bodies to foot their HD, AVF creation and medication costs. Those funding bodies are state and federal government, SOCSO, charitable bodies and the employers of the patients. Participants' stress related to the continuing worries of financial support is an issue that deserved the attention of the nephrology team, as most of them were unemployed with no income. If their financial support is terminated, they would not be able to receive HD treatment, a treatment that their lives depended upon.

Other than that, the study also found that the participants were worried and stress by the frequent interruption of HD treatment due to water or electrical power supply failure. Perhaps they were fearful that when they failed to receive HD, this might lead to acute exacerbations of their illnesses, such as pulmonary oedema, hyperkalemia, cardiac arrest, bleeding secondary to uraemia, or death. They were concerned and felt fear when being asked to go home without HD treatment or did not complete the four hours HD treatment due to electrical power or water supply failure. While waiting for another HD session (two days later), participants were more stressed as they had to control their fluid and food intake more strictly. Some participants even avoided consuming food and drink until they could receive the next HD session. Some

participants made efforts to save money in case they had to pay for the HD treatment in another HD center to continue removing biological wastes and excessive body fluid.

Uninterrupted electricity and water supply are essential prerequisites for effective HD treatment. In order to prevent non-continuity of HD treatment due to electrical power failure, most HD Centers had a stand-by, uninterruptible power source to provide a constant flow of electricity for a short time. Nevertheless, in the event when failure of electricity power supply was unavoidable, nurses usually concentrated more on handling the situation such as contacting the dialysis technician, arranging the next session for patients to have HD treatment in the other HD center if possible, and giving advice on fluid and diet control to the patients. Most of the time, the feeling and psychological aspects of the patients were not nurses' main concern, hence, these related aspect of care was either not or less given any attention. Stress related to water or electrical power supply failure and stricter control of food and drink intake would affect patients' quality of life. This finding was unidentified by previous studies. Thus, this new perspective on the experience of patients with ESRD living with HD in Malaysia, can be further explored.

The participants also highlighted the feeling of uncertainty and fear related to prognosis, outcome, death, future life and kidney transplant. Perhaps this was because the participants realized that HD was not the cure but only to relieve the symptoms of ESRD. Participants felt uncertain because their health was so unstable and they needed to rely on HD as the form of life-sustaining treatment. This finding is similar to the finding reported by Kaba *et al*. (2007) whereby the Greek patients expressed uncertainty related to health instability. Besides that, the participants felt uncertain about their future as they wondered how much longer they might live. Polaschek

(2003) also reported similar findings. Kaba *et al*. (2007) found their patients became anxious and even fearful as they contemplated potential problems, including the possibility of premature death. This study also found participants had fear of pain due to AVF needle insertion. Some of the participants even avoided HD treatment due to this fear. Similarly, this finding was also report in studies done by Herlin and Wann-Hansson (2010) and Aitken *et al*. (2013).

HD must be ongoing and continued lifelong until death or after receiving a kidney transplant. In Malaysia, only 1,841 ESRD patients received kidney transplantation as reported by Lim, Ong and Goh (2012) in the 19th Report of MRTD Registry. Living related donor transplants constitutes 30 to 40% of all kidney transplantation, and unrelated (paid) donors, 60 to 70%, whereas cadaveric transplantation has only accounted for less than 2% of all transplants (Lim, Ong & Goh, 2012). Living related donors are the main source of kidneys for transplantation, especially in the early years in the development of kidney transplantation in Malaysia. If the patient has a potential living donor, the duration to wait may be relatively short. Currently, MOH, private and NGO health care system in Malaysia are actively encouraging patients' family members and close relatives to become kidney donors. However, this study revealed that the participants felt uncertainty and fear towards living related kidney transplant or cadaveric kidney transplant. Most participants were unwilling to have the kidney from their own family members, but they wanted to accept cadaveric kidney transplant (deceased donor) because they feared of the harm that might occur to their family donor. They did not want their family members to suffer from complications of surgery that may worsen their family condition. All the participants expressed that they were waiting for a deceased donor, which has a long waiting list as the donation rate is low in Malaysia. The data derived from the Malaysian Organ Sharing System (MOSS) dated in

19 Mac 2013 showed that 17,084 of dialysis patients in Malaysia were on the National Kidney Organ Waiting List. Similarly, Shih and Honey (2011) reported that the rate for Maori both donor and receiving of organs were much lower than those for non-Maori, with only 2.9% of Maori patients received a kidney transplant. Moran, Scott and Darbyshire (2010) also found their patients hoping to receive a kidney transplant, but they became uncertain for the future while waiting. From my past professional experience, I noticed that the duration of waiting for a cadaveric transplant could be up to fifteen years or even longer, and there was no way of knowing when a suitable kidney would become available. Thus, while waiting to receive a cadaveric kidney transplant, it could be very stressful as the participants would be waiting for an unknown outcome.

5.1.3 Uncertainty and fear

There are obvious advantages to having a kidney transplant. If it is successful, HD is no longer required and many associated problems would disappear such as dietary restrictions, fluid overload, and the general well-being of the patients improved. While they were aware of the advantages of kidney transplant, the participants in this study also shared their feelings of uncertainty and fear towards kidney transplantation because it was like trading from one set of problem (dialysis) to another set of problem (transplantation). The participants felt uncertain and in fear, perhaps they realized that a kidney transplant was not without risk. The participants may encounter complications of transplant surgery, the effects of immune-suppressive drugs and rejection of transplanted kidney. The feeling of uncertainty and fear related to complications, drug effects and rejection of transplanted kidney were also identified by Herlin and Wann-Hasson

(2010). The participants in this study felt uncertain and fear towards living related kidney transplant or cadaveric kidney transplant indicated perhaps they still lacked knowledge about the kidney transplant surgery, the benefits and success rate of kidney transplant, and post transplant care. The studies described by McCann and Boore (2000) and Lok (1996) identified these types of uncertainties as sources of stress for patients and family members. Thus, the participants need appropriate information regarding kidney transplant to relieve their uncertainty, fear and psychological stress towards kidney transplant.

In view of all the above emotional feeling, it is important to acknowledge that having ESRD and HD treatment is a very stressful life event. The information gathered and the findings of this study provided insight into the substantial psychological problem that these HD patients had to cope with. Cruz, Almeida, Fleck and Polanczyk (2009) commented that psychological problem was strongly associated with poor prognosis, health status, and quality of life. Yeh and Chou (2007) and Kohli, Batra and Aggarwal (2011) reported that HD patients who experienced anxiety could lead to mental health problems, thus reduced quality of life and subjective wellbeing. How patients cope with stress is important because it can contribute to greater morbidity and even to earlier mortality (Finkelstein & Finkelstein, 2000). Uncertainty is strongly- linked to suicide (Kaba *et al*. 2007; Ginieri-Coccossis *et al*. 2008). Thus, it is important for health care professional to decrease psychological distress and subsequently elevate patients' quality of life through increased emphasis on the psychological care of patients on HD.

5.2 When life is dependent on haemodialysis

HD is the most common treatment used to treat patients with ESRD in the world, as well as in Malaysia in order to sustain and prolong the patients' life. However, the participants in this study, also suffered from the negative impacts of HD which can arise from the HD process itself, the technology (the HD machine), the vascular access (the AVF or CVC), and the HD facilities.

5.2.1 Dialysis dependency

The participants talked about being dependent on HD treatment. The participants were dependent upon the HD machine to carry out the HD treatment. HD treatment was perceived as the only way to maintain survival. This dependency is consistent with the study findings reported by Hagren *et al*. (2001) and Sadala and Lorencon (2006). Besides that, the participants needed to depend on health care professional to perform HD treatment and HD related procedures. They also depended on family members in daily living activities. The dependence on caregivers is frequently reported in some studies (Hargen *et al*., 2001; Sadala & Lorencon, 2006). This study also identified the participants were dependent on AVF and financial support. Being dependent on HD treatment and HD machine, AVF and financial support is an overwhelming experience. The HD regimes, which treats the patients but does not cure, which sustains their lives but does not heal, causes the life of patient with ESRD that has previously known, but is now permanently altered. They need to live with all those dependencies for their whole life until either death or receiving a kidney transplant.

5.2.2 Diet and fluid restriction

Most of the participants mentioned fluid restriction as the most difficult part of HD related care. This is evident as some participants reported that they felt stress due to dietary restrictions with fluid limitations**.** Mok and Tam (2001) in Hong Kong also reported similar findings. Besides that, fluid and diet restriction also contribute to further restriction and limitation of family and social lives. All these restrictions reported by participants were consistent with the study findings by Kaba *et al*. (2007) and Finnegan-John and Thomas (2013). Kaba *et al.* (2007) found that fluid and dietary restrictions prevents HD patients from participating in social functions. Finnegan-John and Thomas (2013) in London reported that all (118) patients mentioned strict daily restrictions in diet and fluid significantly affected social interactions and leisure activities, and causing difficulties too. For most of the people in Sarawak, having a meal with friends is an enjoyable social function for a family. Fluid and food restrictions prevent patients from participating in this social function. For normal people, being able to enjoy food is particularly important in life. However, for patients with ESRD, fluid and diet restriction is not the only practical problem of a dietary regimen that patients have to cope with, but also a radical change in lifestyle. Thus, the restrictions to fluids and diet affected the patient's quality of life. The patients need sufficient information and guidance to learn and adapt to the restriction of diet and fluid, and social restriction for better wellbeing.

5.2.3 Loss of freedom

The participants have experienced a loss of freedom due to their dependency on the machine,

with fixed schedule in a fixed HD center. Their usual routines were affected by the time spent in the HD center. They could not go anywhere freely. Patients with HD experienced loss of freedom was found in numerous studies like Lindqvist, Carlsson and Sjoden (2000); Hagren *et al*. (2001); Polaschek (2003) and Herlin and Wann-Hansson (2010). Herlin and Wann-Hansson (2010) in Sweden reported that everything revolved around the day in the dialysis clinic. Hagren *et al*. (2001) revealed that holding on to the HD machine meant that the patients lost their freedom. Lindqvist, Carlsson and Sjoden (2000) reported that the patients were unable to go away at short notice; and everything had to be plan carefully because of their scheduled HD treatments. Thus, eventhough HD treatments are well perform in a well-equipped HD center to prolong the patients' lives, the time spent travelling to and from to receive HD treatment, the length of time for HD treatment and the time spent following the treatment regime, gave the participants little space for living. The participants lived in a restricted life, time and work restricted, social interactions and leisure activities were also restricted.

Apart from the time spent on HD, the patients still have time for normal activities but their travelling has to be curtailed. The participants in this study reported that they could not travel far and be away for a long period of time as they had to be back for HD on alternate days. They could only travel to places where there were HD centers. The loss of freedom to travel was one of the issues highlighted by the participants. The study identified the other two factors that restricted the participants to travel were the source of dialysis funding, and the policies and managements of different HD centers. These two factors limited the participants' eligibility to have their HD done in other HD center. This finding was unidentified in previous studies, thus, this could be a unique experience of patients on HD in Malaysia. If there were mutual

understandings and arrangements for all HD centers in Malaysia, the patients would then be free to have their HD in any center and thus allow them to have more freedom to travel.

Individuals' freedom is not limited on physical freedom, but also in terms of autonomy to make one's own decisions. The participants in this study had reported their loss of autonomy to make their own decisions because they were depended on the HD treatment, HD machine and medical technology, family and health care providers, and financial support. Participants on HD could not choose to live life as they wished, nor use their time as they wished due to restrictions imposed by the HD treatment. Restriction on activities and the quality of the activities can have serious impacts on a person's feeling of the autonomy and self-esteem (Jansen *et al*., 2010). Autonomy is a person's basic psychological need that can affect his or her sense of wellbeing (Deci & Ryan, 1985 cited in Jansen *et al*., 2010). Paradise and Kernis (2002, cited in Jansen *et al*., 2010) also cited that high and stable self-esteem were associated with better psychological wellbeing. Thus, this loss of autonomy had led to loss of control on participants' lifestyle, time, work, travelling and social life, which also affected their psychological wellbeing.

5.2.4 Employment challenges

The study found only 11 (39%) participants were able to maintain a full or part time job after the initiation of HD treatments, whereas some participants lost their employment and earning capabilities even though they were still at working age. Besides that, this study also identified many challenges that the participants faced like retaining, changing or finding new employment. Many factors such as dependency and restrictions of HD therapy, fatigue, fear of failure or

malfunction of AVF forced patients to change job or profession, stop working, or forced to retire early. This finding is similar to the study finding reported in some studies (Smith & Soliday 2001; Van Manen *et al.*, 2001; Tong *et al*., 2009). Smith and Soliday (2001) reported that patients are been forced to live a retired life in working-age due to the illness, HD treatment, loss of earning capability and inability to find a job. Van Manen *et al.* (2001) found patient on HD lost their jobs because of impaired physical and psychosocial functioning. Tong *et al.* (2009) also found fatigue and weakness had restricted patients' abilities to work.

Loss of employment or earning capability is an important issue for patients on HD because employment is a source of income in supporting oneself and family in order to be financially independent. Employment also provides other benefits such as improving one's self-esteem and a means of social interaction (Jansen *et al,* 2010). Unemployment is associated with greater psychological problems such as anxiety, depression, and loss of self-esteem. Louis (2010) reported that unemployment among dialysis patients is a source of poor psychological wellbeing and had distinct financial implications, and thus affecting their socioeconomic status. A decline in socioeconomic status could be associated with poorer health outcomes (Cukor *et al*., 2005). Thus, improvements in physical and psychosocial functioning would potentially prevent the patients from losing their employment once their dialysis commenced. However, the management of ESRD in the current nephrology health care setting in Malaysia focuses more on providing HD treatment, HD related procedure, giving medication, giving health education and advice, providing outpatient clinic review to control ESRD symptoms and to prevent HD complications. Nurses working in these settings tend to place less emphasis on the role of vocational rehabilitation care in the management of patients with ESRD. It is necessary for

nurses and other health care professional working in nephrology units to understand those factors that could contribute to unemployment and assist the patients in finding ways to maintain employment and be financially independent.

5.2.5 Financial difficulties

The participants in this present study also experienced financial difficulties due to the cost of HD treatment, AVF creation, medication expenses, daily expenses and loss of employment. Many of them highlighted the high cost of HD is a financial burden which is insurmountable at times. When patients are not selected to receive HD treatment in government hospitals, they are forced to receive the treatment in an NGO or private HD center, where the cost of HD is always much higher than the public HD center. These high HD costs had forced some of the patients' family member to do extra jobs or borrowed money from their employers and friends to foot the bills. The current nephrology team of the public hospitals in Kuching is actively assisting patients to seek financial assistance from federal and state government, NGOs and charitable bodies. Some patients were assisted when applying for welfare allowance from the Community Welfare Department and disability living allowance from SOSCO. This is done before or after the patients initiated HD treatment. However, the study still found that patients experienced financial constraints due to loss of family income, or forced to retire at working age. The disability living allowance or welfare allowance that they received was insufficient to cover transport and daily household expenses. Shih and Honey (2011) reported similar financial support, such as private insurance or state programme, or federal health insurance plans, which paid much of the HD costs. In addition, the patients could also claim disability living allowance. Despite that, the cost

of attending numerous specialist appointments, prescriptions, and maintaining a healthy renal diet were noted to have a negative financial impact. In Iran, despite full medical insurance coverage was available to all ESRD patients, transport expenses to and fro from HD unit using taxis was found to have to be an added financial constraint (Arefzadeh, Lessanpezeshki & Seifi, 2009).

This study found that the cost of HD, AVF creation, and medication funded by the government or other charitable bodies had provided financial reliefs to some of the participants. However, they still experienced financial difficulties as some of them who were single and received only RM60 to RM150 per month, and for those who were married with family received RM300 per month from the Community Welfare Department. In addition, some participants received disability daily living allowance around RM300-400 per month from SOCSO. Nevertheless, this amount of money was insufficient to meet the demands of the current living cost in Malaysia. Thus, it is a challenge for the nephrology team to find a more structured financial assistance mechanism to support this group of patients.

5.3 Adapting into new life with haemodialysis

Most of the participants stated that HD was the best way to help them because it could prolong their lives and relieved them from renal failure symptoms. They were actively adapting themselves into their new life with HD.

5.3.1 Adaptation

In terms of adaptation, the participants had attempted to adjust their lives to the physical, psychological, social and financial effects associated with their disease and HD treatment. They used several adaptation methods such as making adjustments and changes, learning to perform self-care, seeking financial assistance, and skipped HD treatment.

In the initial stage of HD treatment, most participants underwent a certain period of adjustment. All participants actively made adjustments and changes in their lives like dividing their time properly, scheduled their daily activities, or made special arrangement with health care providers if they were away from the usual HD center to ensure they could still receive the HD. This finding is consistent with the finding reported by Hagren *et al.* (2005). Hagren *et al.* (2005) found their patients made some changes in their life, including diet changes and planned their activities with the help of healthcare providers, family and friends in order to cope with their illness and treatment.

After been diagnosed with any illness, an individual needs to make choices and decisions on the treatment. However, been diagnosed with ESRD is a challenge due to its life-threatening nature and highly technical treatment. The choices are limited to few treatment options, such as HD, or PD, or kidney transplant. Without any treatment the patients would die. However, after the initiation HD, the participants experienced the impact of being dependent on HD treatment, HD machine, AVF and health care professionals for survival. HD treatment imposed several restrictions and limitations in patients' life. They needed to have strict dietary and fluid control

as well as having to spend considerable time on treatment. HD patients experienced a loss of freedom and disturbance to their family and social life. All these required significant and major lifestyle adjustments. The participants had the will to live, so all these adjustments and changes were necessary so that HD treatment could fit into the participants' daily living activities, work schedules and social activities.

Many participants learned how to care for themselves. They learned to comply with the diet and fluid restriction; took vital signs and weighing, do priming, starting and turning off the HD procedure. Besides that, some patients also learned how to care for their AVF and how much fluid to be extract during HD. This study finding is consistent with the study finding reported by Hagren *et al.* (2005). Hagren *et al.* (2005) found that patients became accustomed and took over the responsibility for their own treatment and care. HD treatment is complicated and highly technical. The participants' self-care performance is a positive adaptation method. The patients are strongly encouraged to familiarize themselves with the equipment, diet and fluid control and HD machine as HD is a lifelong treatment. The participants who apply self-care management would develop a sense of independence and autonomy that is very important in coping with the disease and its related treatment.

The participants had reported experiencing many vascular access related problems posed by AVF or IJC such as bleeding, chills and rigor due to infection at the insertion site. Infection at AVF site necessitated frequent creation of AVF. Insertion of IJC resulted in pain and inconvenience when patients perform their daily living activities. This finding is consistent with the finding reported by de Andrade and Ferreira (2007) in Brazil. They also found patients receiving HD

through CVC experienced intense bleeding during insertion, hematoma, fever, catheter insertion pain and catheter-related bloodstream infection. Many participants experienced vascular access complication such as poor blood flow, frequent thrombosis or malfunction, and life-threatening bacteremia that were also reported in other studies (Martin-McDonald, 2004; Hagren *et al*., 2005; Tanyi & Werner, 2008). Some participants had frequently undergone re-creation of AVF or re-insertion of CVC because they were unable to receive HD treatment without having AVF or CVC. Some participants need to convert to PD while waiting for AVF to be mature. Besides that, receiving HD three times per week via AVF repeatedly exposed patients to roughly 320 needle punctures per year which could led to considerable pain, both on and between dialysis sessions. Problems like thrombosis or failure of AVF, or clog on CVC, or infection poses stress to patients and dialysis nurses as HD treatment would be interrupted and re-creation of AVF and re-insertion of CVC are needed (Martin-McDonald, 2004; Hagren *et al*., 2005; Tanyi & Werner, 2008). These study findings indicated that although vascular access such as AVF or CVC is a lifeline for patients with ESRD to receive HD, it is also a source of suffering for them. Nurses needed to be aware of the presence and severity of those vascular access-related problems in order to improve care and to assist patients in dealing with this problem more effectively.

Participants and family also actively sought financial assistance from federal or state government department, or SOCSO, or charity bodies to pay for the cost of HD treatment, AVF creation and medication. The family members of participants needed to do extra jobs and borrowed money from employers to pay for HD cost. They also applied to SOSCO and Community Welfare Department for daily living allowance. Their family and friends also provided financial support. This finding indicated that participants and their family were actively solving their financial

difficulties and constraints to ensure the participants could receive HD treatment in order to sustain and prolong life. All these efforts made by the participants and their families could be very stressful. Most of them only received those financial supports after they had initiated HD. The current nephrology team is actively helping patients to seek financial assistance at the pre-dialysis stage or stage four (4) of CKD, before they undergo HD treatment in order to pay for the cost of AVF creation and HD treatment and also for other financial needs. However, some participants only received those financial supports after they have commenced HD for a few months due to the delay in application or approval from funding bodies. The participants and their family members must be very stressful during the waiting period for funding approval. This was evident in this study where most of the participants claimed that they were less stressful and worried only after they had received financial support. Thus, this financial support is very important as it relieved the participants' financial burden, reduce their stress and worry. The dialysis funding and other financial assistance should be available to patients before they commence HD treatment. The challenge is how to provide financial support constantly and continuously for patients at different stages of their disease and treatment during their lifetime.

Most of the participants received HD treatment regularly, but some skipped HD treatment occasionally to cope with their daily living problem. They skipped one session of the HD treatment in a week due to transport problem back and forth the HD center (from Bau to Kuching, around 30 Kilometers), or need to attend some courses related to their jobs. This finding is in contrast with Aitken *et al*. (2013). Aitken *et al*. (2013) found that their patients skipped HD treatment because they could not tolerate the pain due to needling. The participants in this study would only skip HD treatment on the second session of HD in a week. The participants reported

that they would not skip or miss HD treatment during weekends (first or third session of HD in a week) because the duration without HD treatment would be too long, which was four (4) days compared to normal schedule of two (2) days. Participants understood that long duration without HD was very risky, as they would develop acute exacerbation of illness, such as fluid overload, or hyperkalaemia, or uraemia, or bleeding secondary to uraemia, or worse, death. Skipping HD treatment is a negative coping strategy and is consider as non-compliance to HD treatment in the Nephrology setting. This finding revealed that even the participants were noncompliant to HD treatment occasionally; however, they still had the will to live as they only skipped the second session of HD treatment either on Wednesday or Thursday, but not during weekends to avoid an acute exacerbation of illness. Nevertheless, the patients are not encouraged to skip even one HD treatment session in a week because regular HD treatment is essential for long-term survival. The patients should been advised to use only appropriate or positive coping strategies to overcome their daily life problems.

5.3.2 Restructuring family and social life and relationship

The HD treatments also had impact on the participants' family. The participants and their family members needed to change their family roles and responsibilities. The participants' roles as fathers or mothers had to change, as they were unable to perform their original roles. Some participants were unable to carry out their adult responsibilities but instead their old parents had to take care of them. Some young daughters have to take the responsibilities of caring their sick mothers. Participants' brother or sisters have to take over the roles to care for nieces or nephews. An old grandmother may need to take care of her grandchildren. Change in family roles and

responsibilities in order to cope with ESRD and HD treatment identified in this study are similar to the finding reported in some studies (Smith & Soliday 2001; Polaschek, 2003; Martin-McDonald 2004; Al-Arabi, 2006; Lee *et al.*, 2007; Tong *et al.*, 2009). Smith and Soliday's (2001) study revealed that when patients were fatigued, their capacities to provide psychosocial care through engaging in play activities and school activities for their children were reduced. The fatigue was more pronounce in women on HD and affected their ability to care for their family and undertake domestic chores. Polaschek (2003) found a change of balance in physical and emotional strength between patients and their partners due to the disease such as the "weak became strong and vice versa". Al-Arabi (2006) also reported that patients experienced inability to participate in strenuous activities such as camping with their children and family, non-attendance at family activities that occurred during their HD treatment. Lee *et al.* (2007) indicated patients, especially mothers were unable to care for their children in the way they wanted to, could not carry out her everyday activities as the mother. Patients were dependent on family members, including their children as reported in this study are similar to finding found by Tong *et al.* (2009).

This study found that the participants and family had to give up some responsibilities and activities. The participants had positive changes in their family relationships that included support and enhanced personal relationships. When a family member had a serious illness (ESRD), the other family member was also been confronted with many related problems. Thus, they had to make major changes in their usual routines in order to accommodate the illness' demands. However, this study did not address the effect of the HD on the psycho-social functioning of the family.

5.3.3 Coping

The participants also used some coping strategies such as being positive, being accepted, peer learning and support, seeking help from the support system, prayer, religion and faith in God to cope with this life threatening disease and highly technical treatment. Many participants attempted to be positive to get the benefits of their treatment. They used positive thinking, be happy and try to forget that they were sick. Some of them compared themselves to cancer patients, and concluded that they were better off than cancer patient as most of the cancer patients could not eat, but they still could eat. This study revealed that patients adopted a present day perspective in order to cope with this life sustaining treatment. Correspondingly, Curtin *et al.* (2002) showed that patients living in HD tolerated uncertainty by predominantly concentrating on the present. They coped with the distress of having HD by blocking out thoughts of their illness and treatment. Tanyi and Werner (2008) highlighted patient's efforts to suppress distressing emotions and focused on the present, in an effort to cope with ESRD and HD treatment. Kohli, Batra and Aggarwal (2011) reported that the patients on maintenance HD in India, applied positive reappraisal, seeking guidance and support and avoid thinking about the stress.

Being positive is a good coping strategy that could be useful for patients on HD. The patients with positive attitudes had self-perceptions of wellness rather than sickness, results in better adjustment to chronic illness. The well-adjusted patients minimized their losses and emphasized their abilities. They were achievement oriented, accepted their limitations and maintained an interest in hobbies and activities. Kohli, Batra and Aggarwal (2011) commented that behavioral attempts would help HD patients in getting new sources of satisfaction, and enhance the

effectiveness of dealing with various problems in personal, familial, societal, and occupational disturbances. In contrast, those patients that have negative thinking were less well-adjusted led to only lives revolved around dialysis, letting it become their main focus in life. They tended to have more mood swings, loss of friendships and less participation in social activities. Thus, the patients who apply the positive attitude would have better adjustment, and improve their physical, emotional and social wellbeing.

Acceptance of chronic illness (ESRD), including the need of routine HD treatments, and the various restrictions associated with this chronic disease revealed that the participants in this study shared positive feelings and emotions towards their illness and treatment. HD therapy represented a fine line between life and death for patients suffering with ESRD so the patient with ESRD just had to go with it. Participants who accepted HD were good as they applied positive coping strategy to cope with the effects of disease and treatments. After the participants accepted the HD treatment as unavoidable that they just needed to get through, they would be willing to learn and incorporate the necessary restrictions associated with HD. Then, the participants were able to manage their treatment schedule and restrictions well. Effective adapting and coping are important in patients on HD, as it is extremely difficult for patients to get used to HD treatment, HD machine and the HD associated effects (Logan, Pelletier & Hodgins, 2006). Kohli, Batra and Aggarwal (2011) commented that acceptance would help HD patients in getting new sources of satisfaction, and enhance the effectiveness of dealing with various problems in personal, familial, societal, and occupational disturbances.

All of the participants in this study sought help from family members, friends, other patients on

HD, nurses and other health care providers and funding bodies to adapt and cope effectively with HD. The family was been found to be the most important source of support to help patients to cope with HD treatments in terms of roles and responsibilities adjustment, transportation, emotional and financial support, diet and fluid preparation and restriction, and in the social life rearrangement. Besides that, health care professionals, especially nurses, assistant medical officers, and doctors were providing HD treatments, advice, guidance and health information. The participants received emotional, informational, material and financial support, thus, reduced the effects of stressful. Integration of psychological and material support for better health care of the patient is the essence of the social support system (Theofilou, 2011e). Social support would help patients to have more adherence to HD treatment, dietary and fluid restrictions, and effectively relieved patients' stress, anxiety and depression (Theofilou, 2011; Theofilou, 2012). Social support offered to patients is positively associated with higher quality of life in HD patients (Theofilou, 2012e). Thus, family, nurses and other health care providers were identified to have good and supportive relationship with the participants. Attending to an HD unit can be a new social outlet for patients on HD as they could make good friends with both staff and other patients who help them to adapt and cope with HD better. This could be due to the Malaysian culture and religious beliefs that people are willing to provide help in preventing stress, anxiety, depression and mood changes in patients with chronic illness.

Some participants were comfortable leaving their decisions to the health care providers. However, many participants actively learned about their illness, diet and fluid restrictions and HD treatment from other HD patients besides the health care providers. When the participants encounter any problems, they always approached the other patients who were with them. The

participants tended to help each other and provided support for each other. They preferred to receive information, advice and support from the other HD patients who had same experiences. This peer support and learning provided the opportunity for the participants to share experiences that might help them to solve problems related to HD and improved their quality of life. The other ESRD patients who had plenty of experiences in managing the HD treatment became teacher, family member, friend or colleague to the participants. Learning from others who are coping well can act as a source of inspiration and hope, especially where there is clear, explicit information available about what other patients are doing in order to function well. The "experienced patient" is a positive resource that could provide education and peer support in empowering newly diagnosed patients.

The participants coped with their sadness, dislike of HD treatment, worries, stress and fear through prayer, reading a religion's book, visiting the temple, listening to religious song, receiving counseling from the church and living in hope. They prayed to God together with their pastor, family members and church members for recovery and better outcome of disease. This coping mechanism is consistent with findings reported in some studies (Sadala & Lorencon, 2006; Yodchai *et al.,* 2011; Finnegan-John & Thomas, 2013). Yodchai *et al.* (2011) reported that patients in Thailand adapted to stress and depression through religious beliefs. Sadala and Lorencon (2006) found the patients on HD in Brazil praised the Lord and prayed for the machine, for the nurses and for everything. The patient believed that God could heal anything. They also believed God could heal their kidneys, restore it, made a miracle if He wants to. Besides that, Finnegan-John and Thomas (2013) found patients in London also depended on their faith in prayer, doing meditations, and having beliefs in a higher power by worshipping in church, temple

or mosque to help coping with their disease. Religion can help patients understand the value of life. When individuals have uncertainty in their lives, religious beliefs become more important particularly if the religion is an important part of their cultures. Finnegan-John and Thomas (2013) reported that the patients' faith linked them into a religious community, offering a support network, enabled them to keep an existential perspective over their condition. Prayer, religion and belief in God helped the patients to concentrate, gave them a sense of control over their lives, helped them relax, provided hope and made them comfortable and accepting their health status. Thus, religious beliefs and spiritual support are important to patient's overall sense of wellbeing. Therefore, providing spiritual support to patient with HD is essential. The challenge is how to provide this spiritual support effectively, especially when patients on HD are from different ethnic groups who have different cultures, religions and beliefs.

5.4 A sense of hope in the unknown future

The findings of this study provided insight into how the participant developed their sense of hope and looking forward to their future. The participants developed this hope because HD had prolonged their lives and they had accepted it. They viewed HD center as a place that of hope because it had improved their physical wellbeing.

5.4.1 Hope to restore good health, attain pre dialysis status, live healthily

The participants hoped that they could still restore good health, attain pre dialysis status and live healthily. This hope for good health is consistent with the findings reported by Lindqvist,

Carlsson and Sjoden (2000). Lindqvist, Carlsson and Sjoden (2000) reported that their patients expressed their "wish for independence and normalcy". They also wished to have control on their own lives. The participants in this study hoped to restore health because of the intermittent nature of HD treatment, thus, they had a very great difference on their body fluid volume status, electrolytes balance on dialysis days and non-dialysis days. Fluid volume overload and metabolic abnormalities such as hyperkalemia could affect cardiac function and may lead to sudden death. Besides that, even their lives have been prolonged by HD, they still suffered with multiple HD associated effects and complication of chronic illness. They felt uncertain towards their prognosis and outcome of treatment. They did not want to depend on HD for the whole of their life. They did not want the HD treatment to be permanent. They wanted to be free from it. They also desired for better quality of life. This hope is interrelated with the hope for kidney transplant because the participants understood that they could attain pre-dialysis status and live like other healthy people if they have a successful kidney transplant.

5.4.2 Hope for a kidney transplant

The possibility for kidney transplant in the future had provided hope for all the participants. The participants were hoping and waiting for kidney transplantation because they would be able to escape from dependence on HD. They look at the positive aspects of a possible transplant because they knew that it offered a possible cure for ESRD. Participants also understood that kidney transplant offered the best potential for full rehabilitation to normal life in comparison to HD treatment even though some had a feeling of uncertainty and fear towards kidney transplant. This sense of hope, of receiving a kidney transplant was dominant in this study and is in

concurrence with many other studies (Hagren *et al.*, 2001; Polaschek, 2003; Herlin & Wann-Hansson, 2010; Moran, Scott & Darbyshire 2010; Calvey & Mee, 2011).

Herlin and Wann-Hansson (2010) reported that the hope for transplantation made patients feel that life consisted more than being on HD treatment. This hope allowed them to handle the feeling of lack of freedom as the time they spent on HD had limited their life. Kidney transplantation would allow patients to adapt to a more sustainable way of life and a more promising future if compared to receiving HD. After a kidney transplant, they would have a better quality of life, better survival, better physical and emotional wellbeing. They would be able to return to work, have less restriction in diet, fluid intake and daily living activity and thus freedom to live. However, another challenge for patients on HD to become an eligible and suitable recipient of kidney transplant, they needed to comply with HD treatment, medication, diet and fluid restriction. They also needed to fulfill the cadaveric kidney transplant waiting list criteria such as be matched appropriately with a donor, physically stable, no other serious illness like cardiovascular disease; liver disease; or cancer, and fit to undergo kidney transplant surgery.

5.4.3 Hope for employment

About half of the participants in this study who depended on regular HD were unable to work at their former job, although 39% (11) of them were able to continue to do so. Those who were unemployed expressed their hope to return to work either full or part-time. They desired to continue working to earn more money even though some of them have received monthly financial support (Pencen Ilat) from SOCSO, and financial assistance from the Community

Welfare Department. They had desire for a better life that made them to have hope for re-employment. They also suggested that the government should provide suitable jobs for patients living with HD. In the current nephrology practice, nurses only informed nephrologists to refer patients to a medical social worker when patients expressed their employment's needs. The employment needs assessment was not carry out routinely. This hope of employment clearly indicated that nurses and other health care professional should find ways to assist patients in vocational rehabilitation.

5.4.4 Hope for freedom to live

The study reported that many participants hoped for freedom to live. The hope for freedom to live could become a reality if they had a successful kidney transplant. After a kidney transplant, the participants need not be dependent on HD that has restricted their freedom. They do not need to travel to HD center every alternate day. They will be free to go wherever they like, although they still need post kidney transplant care.

Besides that, the participants also hoped for a more advanced HD machine that was small enough, wearable and portable that could be carried anywhere, and could perform HD treatment any time. With such a portable HD machine, they would not have any more restriction and could go to anywhere they like, and thus, fulfilling their desire for freedom to live.

The current HD machines are heavy, bulky, attach to a wall electrical outlet and require many gallons of water to run. Patients have to be hook up to the machine for the process of dialysis

thus restricted the patients' freedom. The participants believed that the chance for this hope or dream would become a reality just like the evolution of the desktop computer to laptop, and the bulky mobile phones to the latest smart phones. This hope was unidentified in previous studies. It offered a new perspective of patients with ESRD on HD.

A series of experiments attempting to invent a truly "wearable artificial kidney" or device that would allow patients to ambulate whilst being treated, and so offer the possibility of outpatient therapy has been report in many studies (Ronco, Davenport & Gura, 2011). However, there are still many modifications required and technical challenges to overcome with research and innovation. Patients on HD still need to wait for the scientific advances to solve these problems one by one.

The study revealed that although HD had prolonged the ESRD patients' lives, they still suffered from the negative effects of HD, such as physical adverse effects, restricted life, loss of freedom and employment, financial difficulties, unstable health status and potential premature death. They had developed a sense of the hope and looked forward to the future because they desired for better quality of life. All those hopes expressed by the participants had helped them to adapt to their illness and treatment and as a strategy for coping. Hope is referring to a belief in a beneficent yet uncertain expectation of achieving a better future, which is realistically possible and personally significant to the hoping person. Hope is an important predictor of adjustment to ESRD and subsequent HD. Thus, hopefulness could serve to lessen the emotional impact of ESRD and HD treatment, by empowering the patients to refrain threats as challenges. Patients should be help, to have the feeling of hope at all time. A higher hope predicted reduced anxiety,

depression, reporting of symptoms and burden related to kidney failure, and improved mental health and quality of life (Billington, Simpson, Unwin, Bray & Giles, 2008).

From the study findings, it could be deduced that there are still gaps in the delivery of nephrology nursing services in addressing the problems of patients on HD in Sarawak, thus warranting attention. The existing nephrology nursing and medical services are insufficient to attend fully to the needs of patients living with HD, such as psychological care, rehabilitation, employment, spiritual; moral and emotional support for patients, as well as for their family. When nurses are planning interventions to facilitate the patients' physical, psychological and social adaptation, their spiritual and religious beliefs should be considered in order to provide a more holistic care.

5.5 Summary

Patients with ESRD experienced positive and negative impacts of HD treatments. HD treatments relieved their renal failure symptoms and extended their lives. However, they encountered paradox, numerous restrictions and losses, physically, psychologically, socially, emotionally and financially. The patients realized that their life was dependent on HD as life-sustaining treatment regime. They also understood that they were dependent upon an HD machine for life support, and dependence on healthcare professionals to perform HD and HD related procedure. Therefore, when HD has imposed several restrictions and losses on their lives that consequently affected their quality of life, they actively and positively adapted and used some coping strategies to counter its negative impacts and to retain the will to live. Patients actively made adjustments and changes; learn to perform self care; adapt to pain; dealing with vascular access problems; and

seeking financial assistance to adapt to problems and challenges associated with HD. Besides that, they applied being positive; accepting; seeks help from the support system; prayer, belief and faith in God; and living in hope in order to cope and manage their lives with HD effectively. The patients as well as family need to restructure their lives and relationship by change of family roles and responsibilities, restructure employment and social activities, reconstructing a new relationship with other dialysis patients, friends and health care professionals. They hoped to restore good health, attain pre dialysis status and live healthy. They also hope for a kidney transplant, hope for employment and hope for freedom to live, as they desired for better quality of life. The patients were thankful and appreciative for the availability of the HD treatment, HD machines and financial assistance to sustain their life. However, they were stressed due to the complications of AVF, water shortage and electricity supply failure, diet and fluid restrictions, loss of freedom, and financial difficulties. The patients also felt uncertain and fearful towards their prognosis, outcome of their lives and their futures as they understood that their life expectancy is less if compared to general populations. Although they hoped for kidney transplantation, they also had uncertainty and fear toward it, as the transplantation surgery and subsequent treatment was not without risk. The existing Nephrology nursing and medical services are still insufficient to fully address the need of patients living with HD such as psychological care; rehabilitation; employment; spiritual, moral and emotional support, thus need more interventions.

CHAPTER 6

CONCLUSION

6.0 Introduction

This final chapter presents the implications of the findings and recommendations for nursing practices, patient educators, policy makers and future research. It also discusses the limitations of the study.

6.1 Implications and recommendations for nursing practices

Fatigue often decreases patients' physical functioning that leads to physical limitations and in turn affects the ability to hold down a full-time job and participate in social activities. As a result, they may feel that they lost control of their lives. Nevertheless, fatigue is the least attended symptom for ESRD patients on HD. Lee *et al*. (2007) commented that fatigue should not be simply accept as part of the haemodialysis effects, rather it must be actively addressed so that patients can have a better quality of life. Thus, it is recommend that nurses should actively and effectively assist patients to address fatigue and physical disability, and assist them to develop coping strategies to prevent and to respond to it. Theofilou (2011) reported that exercise programme improves the psychological status, quality of life and work capacity of haemodialysis patients. As such, nurses should encourage patients to do light physical exercise to minimize fatigue, to increase their physical strength and to improve their physical capability. If patients are

able to manage and decrease their level of fatigue and increase their functional ability, they would be able to improve their quality of life.

Besides that, psychological effects such as sadness, worry, stress, uncertainty and fear were found among the participants in this study. The psychological aspect of patients has not given enough attention by the nephrology team. The psychological problems of patients on HD are not routinely assesse, thus, this aspect of care is normally been left out. Therefore, it is recommend that a structured professional psychosocial support for patients with ESRD on maintenance and regular HD treatment should be made available in all Nephrological care settings. Nurses should perform routine screening to identify patients' psychological symptoms during their regular clinic visits. Once a patient is found to have problems such as worries related to electrical power supply failure, dialysis dependency and financial dependency which are unavoidable or beyond their control, nurses can then provide moral support and counseling to the patients. Nurses should act as listeners, counselors and advocates to the patients accordingly. Nurses may teach patients some non-pharmaceutical therapies such diversional therapy, relaxation training and music therapy in order to reduce their psychological burdens.

In addition, regular needs assessment should be conduct on these patients in order to explore their psychological, social, and spiritual needs. The aim of the needs assessment is to design a comprehensive psychological and counseling support service within the renal care settings. There should also be a mechanism to refer those patients who exhibit more serious psychological symptoms to a psychiatrist or psychologist in order ensure proper psychological care and to prevent mental disorders.

The participants in this study were found to actively cope with their illness and HD treatment through religious and spiritual support. Unfortunately, the current nephrology practice focuses very little on the spiritual care. Therefore, it is recommend that when nurses formulate the care plan for the patients, their spiritual and religious beliefs should been taken into consideration. This would ensure a holistic approach to facilitate the patients' physical, psychological and social adaptation to their conditions.

The participants also voiced their desire to continue to work or to been employed in order to have money to support their treatment and to have a better quality life. They also hoped for suitable job to be provided by government. Therefore, it is recommended that nurses refer these patients to a social worker on a regular basis. In turn, vocational rehabilitation such as job re-training, and job placement can be arranged through the social worker so that patients are able to generate their own income to improve their financial status.

6.2 Implications and recommendations for patient educators

The findings of this study also have implications for patient educators. The participants in this study expressed that they learned to cope with their illness and treatment with the assistance of HD staffs. They needed information to understand their disease and the impact of their disease and treatment on their life. Therefore, nurses, as patient educators, should explain clearly their disease, treatment options and to help them to match their readiness and lifestyle needs for a particular mode of HD therapy. For patients who are computer-literate

and have access to computer, the use of computers to provide educational interventions such as internet education sessions will potentially enhance their understanding of disease and HD treatments.

The participants highlighted that they preferred to learn from other HD patients (peer learning) who have same experiences like them as some health care providers would not discuss all options, but only what they thought was best for the patients. Most patients can be a resource and a conduit for other patients. However, the current public, private or NGO HD centers in Kuching have not established any Patient Support Group. Therefore, it is recommended that a Patient Support Group should be established. Patient educators should consider inviting those long-standing HD patients who have well managed their disease to participate in the Support Group. These patients should been carefully screened by the nephrology health care professionals and be given training as to be effective in their roles to provide quality care to the patients. This Patient Support Group may give advice and provide assistant to ESRD patients who are newly diagnose and need HD treatment. They can share knowledge and skill in self-care management such as before commencement of dialysis, during dialysis, or talk about what life is as a dialysis patient, what restrictions, diet and fluid control and the need for medication compliance. It is expect that significant commitment from the patients, health care professionals and volunteers are need to ensure the success of the support group. In addition, resources would also been needed to develop educational and training materials. Nevertheless, any effort towards improving the patients' quality is a worthwhile effort.

Krueger (2009) and Mitchell *et al*. (2009) commented that the hope for a kidney transplant is an important factor in people's ability to cope with ESRD and HD therapy. However, the participants in this study were uncertain and fearful towards kidney transplant. They were worried of the surgery, post transplant care and its complications even though they were hoping to have a transplant. Moran, Scott and Darbyshire (2010) suggested that nurses should engage in open and honest discussions with patients in relation to kidney transplantation so that they are able to recognize and address patients concerns about kidney transplantation. Therefore, it is been recommended that patient educators must equip themselves with knowledge and understanding about the patient's perspective towards kidney transplant. They should provide active counseling and education programme to assist patients to meet the criteria for the transplant, address their concerns and worries about transplantation, and discuss the possibilities for live donor transplantation. Patients' educators should also reassure the patients that adjusting to transplant is manageable and this can improve their quality of life.

6.3 Implications and recommendations for policy makers

Financial support is very important for patients in order to relieve their financial burden, reduce their stress and worry. Therefore, dialysis funding and other financial assistance should be made available to patients before they commence HD treatment. The welfare living allowance or social security disability daily living allowance is not enough to cover the participants' transport fee and other daily household expenses. In addition to financial difficulties, the participants also worried about the continuity of the financial assistance. Therefore, the nephrology team should recommend to the policy maker of dialysis funding bodies, Community Welfare Department,

SOCSO, and charitable bodies to have a more structured and adequate financial support to cover all expenditure for needy ESRD patients.

Psychosocial care is currently lacking for HD patients in Malaysia. A unique aspect of HD services in Malaysia is that above 60% of these services are provide by private and NGO HD centers. Patients receiving HD care in a private and NGO dialysis center do not have easy access to the psychosocial support system. The private and NGO HD health care providers do not refer patients to social workers or psychologists since this service is not included in the dialysis fund which they received from the federal or state government, or national insurance fund from SOCSO. Therefore, it is recommend that those involved in health policies and health-funding agencies in Malaysia should consider adding the cost of psychological and social care together with dialysis funding in order to provide psychosocial care, improve clinical outcomes and the overall wellbeing of ESRD patients on lifelong HD.

6.4 Implications and recommendations for future research

This study finding can provide a basis for future research, such as to investigate the patients' perception towards kidney transplant in-depth, as the patients were uncertain and fearful towards kidney transplant although they hoped to receive it. Other than that, the psychological effects exerted by worrying about the continuity of financial suppod, and water and electricity power-supply failure, that the participants experienced can also be further explore. This study found that the participants coped better through prayer, religion belief and faith in God. The religious beliefs and spirituality of patients on HD also require further examination. It is suggested that a

study to investigate the relationship between religious belief or spirituality and mental health of patient on HD should be carried out.

The participants reported that both and their family members and they themselves had changed their roles and responsibilities. However, this study did not address the effect of the HD towards the psychosocial functioning of the family. Thus, it is recommended that a study to explore the experience and psychological functioning of family caregiver of patients with ESRD on HD. The findings of such studies would be helpful to the family caregiver of ESRD patients in coping with patients' illness and HD treatment.

Some of the participants of this study were able to retain their job but some were been forced to change job or retire. The future research may explore more on the employment challenges, or to investigate factor contributes to job retention or unemployment among patients living with HD. It is also suggested that future research should be done to a larger population, including participants from different age groups, financial status and educational levels in order to provide more comprehensive finding.

6.5 Limitations of the study

The limitation of this research is the duration of the participants receiving HD is different, ranging from 7 months to 26 years. The participants who received HD for a longer duration may have different experiences compared to those who had undergone HD for a short period. Thus, this might have influenced the study findings. Other than that, the inexperience of the researcher

in qualitative data analysis might also have an impact on the study findings. Nevertheless, I had made every attempt to maintain the integrity, objectivity, and openness in evaluating the data under close guidance of study supervisors, thus, that effect could have been minimized.

6.6 Conclusion

This qualitative study highlighted the impact HD treatment on the lives of patients with ESRD. There were four themes found: "living with the paradox"; "when life is dependent on HD"; "adapting into new life with haemodialysis" and "a sense of hope in the unknown future". HD is one of the treatment modalities to sustain and prolong the life of patients with ESRD. However, it also results in limitations and adversities on these patients' life as their health and survival dependent on HD. Participants in this study experienced a host of adverse effects such as physical limitations, restricted life, loss of freedom, employment challenges, financial difficulties, vascular access related problems and changes in family roles and responsibilities. In addition, they felt sadness, fearfulness, uncertainty and worries. Despite all these problems, the majority of the participants displayed positive adaptive behaviors to cope. They actively made adjustments and changes, restructured their family roles and relationship, learnt from peers, sought help and assistance from their support system, strengthened their belief in God, prayed, and lived in hope. Some participants hoped for kidney transplant, had freedom to live, restored good health, attained pre dialysis status, lived healthily, and returned to job. This study identified gaps in the delivery of nephrology nursing services in addressing the holistic nursing care for patients on HD in Kuching, Sarawak in terms of psychological care; rehabilitation; employment; spiritual, moral and emotional support. Thus, this study suggests that in order to provide a more

holistic care, a more structured psychological care; rehabilitation in employment; spiritual, moral and emotional support; and a more structured financial assistance should be provided to these patients, as well as their family. Future research should explore the employment challenges or factor that contribute to job retention or unemployment among patients living with HD in depth.

REFERENCES

Abrandt, M. (1997). Learning Physiotherapy: The impact of formal education and professional experience. Linkoping Studies in Education and Psychology. No. 5

Agency for Healthcare Research and Quality (2000). Determinants of disability in patients with Chronic renal failure. Retrieved from http://www.ahrq.gov/clinic/epcsums/ renalsum.htm

Aitken, E., McLellan, A., Glen, J., Serpell, M., Mactier, R., & Clancy, M. (2013). Pain resulting from arteriovenous fistulae: prevalence and impact. *Clinical Nephrology, 80* (11), 328-333.

Akoochekian, S.H., Ebrahimi, A., & Samooei, R. (2002). Stress and Mental Disorders in hemodialysis patients. *Journal of Research Medical Science, 7*(4), 57-65.

Al-Arabi, S. (2006). Quality of life: subjective descriptions of challenges to patients with end stage renal disease. *Nephrology Nursing Journal, 33*(3), 285-291.

Allon., M., & Robbin., M.L. (2002). Increasing arteriovenous fistulas in hemodialysis patients: Problems and Solutions. *Kidney International, 62*, 1109-1124. Retrieved from http://www.esrdnet11.org/assets/fistula_first/article_allon2002.pdf

Arefzadeh, A., Lessanpezeshki, M., & Seifi, S. (2009). 'The cost of haemodialysis in Iran', Saudi. *Journal of Kidney Disease and Transplants, 20*(2), 307-311. Retrieved from http://www.sjkdt.org/article.asp7issn.

Australian & New Zealand Dialysis & Transplant Registry (2011). The 34th Annual report: ANZDATA Registry 2011 report, Adelaide: ANZDATA Registry. Retrieved from www.anzdata.org.au/v1/annual_reports_download.html.

Banasik, J., & Copstead, L. (2001). *Pathophysiology: Biological & behavioral perspectives* (2nd ed.). New York, NY: W.B. Saunders.

Barracca, A., Pili, G.F., Spina, M., Murgia, M., Menneas, A.P., & Manca, O. (2002). Temporary vascular access for haemodialysis: is infection still the most important complication? *Giornale Italiano Di Nefrologia: Organo Ufficiale Della Società Italiana Di Nefrologia, 19* (1), 44-48. ISSN: 0393-5590.

Bay, W.H., Van Cleef, S., & Owens, M. (1998). The hemodialysis access: preferences and concerns of patients, dialysis nurses and technicians, and physicians. *American Journal of Nephrology, 18* (5), 379-383.

Bayat, A., Kazemi, R., Toghiani, A., Mohebi, B., Tabatabaee, M.N., & Adibi, N. (2012). Psychological evaluation in hemodialysis patients. *Journal of Pakistan Medical Association, 62*(3) (Suppl 2), 1-5.

Bernado, J. C. (2009). *The Psychology of Personality: Viewpoints, Research, and Applications*. (2nd ed.). Retrieved from http://*books.google.com.my/books?isbn=1405136359*

Billington, E., Simpson, J., Unwin, J., Bray, D., & Giles, D. (2008). Does hope predict adjustment to end-stage renal failure and consequent dialysis? *British Journal of Health Psychology, 13* (4), 683–699.

Burns, N., & Grove, S.K. (2005). *The Practice of Nursing Research* (5th ed.). Elsevier Saunders. St. Louis.

Calls, J., Rodríguez Calero, M.A., Hernández Sánchez, D., Gutiérrez Navarro, M.J., Juan Amer, F., Tura, D. & Torrijos, J.J . (2009). An evaluation of pain in haemodialysis patients using different validated measurement scales. *Nefrología, 29* (3), 236-243.

Calvey, D., & Mee, L. (2011). The lived experience of the person dependent on haemodialysis. *Journal of renal care, 37*(4), 201-207.

Caplin, B., Kumar, S., & Davenport, A. (2011). Patients' perspective of haemodialysis-associated symptoms. *Nephrology,Dialysis,Transplant, 26* (8), 2656-2663. doi: 10.1093/ndt/gfq763.

Caress, A., Luker, K., & Owens, G. (2001). A descriptive study of meaning of illness in chronic renal disease. *Journal of Advanced Nursing, 33*(6), 716-727.

Chen, C.K., Tsai, Y.C., Hsu, H.J., Wu, I.W., Sun, C.Y., Chou, C.C.,…Wang, L.J. (2010). Depression and Suicide risk in hemodialysis patients with chronic renal failure. *Psychosomatics, 51* (6), 526-528.

Christensen, A.J., & Ehlers, S.L. (2002). Psychological factors in end stage renal disease: An emerging context for behavioral medicine research. *Journal of Consulting and Clinical Psychology, 70*(3), 712-724.

Cleary J., & Drennan J. (2005). Quality of life of patients on haemodialysis for end-stage renal disease. *Journal of Advanced Nursing,51*(6), 577-586.

Cohen, M.Z., Kahn, D.L., & Steeves, R.H. (2000). *Hermeneutic phenomenological research: A practical guide for nurse researchers*. Thousand Oaks: Sage.

Cohen, S., Underwood, L., & Gottlieb, B. (Eds.) (2000). *Social support measurement and interventions: A guide for health and social scientists*. New York: Oxford. Retrieved from http://www.psy.cmu.edu/~scohen/CohGotUnd2000.pdf

Corrigan, R.M. (2011). The experience of the older adult with end stage renal disease on haemodialysis. Retrieved from https://qspace.library.queensu.ca/bitstream/1974/6724/7/Corrigan_Rebecca_M_201109_MSc.pdf.

Cruz, L. N., Almeida Fleck, M. P. D., & Polanczyk, C. A. (2009). Depression as a determinant of quality of life in patients with chronic disease: data from Brazil: Springer-Verlag. *Social Psychiatry and Psychiatric Epidemiology, 45*(10), 953-961. doi: 10.1007/s00127-009-0141-2. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19771379

Cukor, D., Cohen, S. D. Peterson, R. A. & Kimmel, P. L. (2007). Psychosocial aspects of chronic disease: ESRD as a paradigmatic illness. *Journal of the American Society of Nephrology, 18*(12), 3042–3055.

Cukor, D., Coplan, J., Brown, C., Friedman, S., Cromwell-Smith, A., Peterson, R.A., & Kimmel, P.L. (2007). Depression and anxiety in urban hemodialysis patients. *Clinical Journal of*

American Society of Nephrology, 2(3), 484-490.

Cukor, D., Coplan, J., Brown, C., Peterson, R.A., & Kimmel, P.L. (2008). Course of depression and anxiety diagnosis in patients treated with hemodialysis: a 16-month follow-up. *Clinical Journal of American Society of Nephrology*, 3(6), 1752-1758.

Cukor, D., Peterson, R.A., Cohen, S.D., & Kimmel, P.L. (2006). Depression in end-stage renal disease hemodialysis patients. *Nature Clinical Practice, Nephrology, 2*(12),678-687.

Curtin, R.B., Mapes, D., Petillo, M., & Oberley, E. (2002). Long-term dialysis survivors: a transformational experience. *Qualitative Health Research, 12*(5), 609–624.

Davison, S.N. (2003). Pain in hemodialysis patients: prevalence, cause, severity and management. *American Journal of Kidney Disease, 42*(6), 1239-1247.

Davison, S.N, & Jhangri, G.S. (2005). The impact of chronic pain on depression, sleep, and the desire to withdraw from dialysis in hemodialysis patients. *Journal of Pain and Symptom Management, 30*(5), 465-473.

de Andrade, D., & Ferreira, V. (2007). Central venous access for haemodialysis: prospective evaluation of possible complications. *Journal of Clinical Nursing*, *16*(2), 414-418.

Denhaerynck, K., Manhaeve, D., & Dobbels, F., Garzoni, D., Nolte, C., & De Geest, S. (2007). Prevalence and consequences of nonadherence to hemodialysis regimens. *American Journal of Critical Care, 16*(3), 222-235.

De Vos, A.S., Strydom, H., Fouche, C.B., & Delport, C.L.S. (2005). *Research at grass roots: For the social science and human service professions* (3th ed.). Pretoria: Van Schaik**.**

Dickinson, D. M., Bodfish, L. J., Pisoni, R. L., Akizawa, T., Locatelli, F., & Akiba, T. (2000). International variation in the employment status of hemodialysis (HD) patients: Results from the DOPPS. *Journal of the American Society of Nephrology, 11,* 229a.

Experience. (2014). *Dictionary.com Unabridged*. Retrieved from Dictionary.com website: http://dictionary.reference.com/browse/experience

Figueiredo, A.E., Viegas., A, Monteiro. & M, & Poli-deFigueiredo, C.E. (2008). Research into pain perception with arteriovenous fistula (AVF) cannulation. *Journal of Renal Care, 34* (4), 169-172. doi: 10.1111/j.1755-6686.2008.00041.x.

Finkelstein, F.O., & Finkelstein, S.H. (2000). Depression in chronic dialysis patients: Assessment and treatment. *Oxford Journal of Nephrology Dialysis Transplantation, 15* (12), 1911-1911. Retrieved from http://ndt.oxfordjournals.org/content/15/12/1911.long

Finnegan-John, J., & Thomas, V. J. (2013). The Psychosocial Experience of Patients with End-Stage Renal Disease and Its Impact on Quality of Life: Findings from a Needs Assessment to Shape a Service. *International Scholarly Research Notices Nephrology*, vol. 2013, Article ID 308986. doi:10.5402/2013/308986

Fresenius Medical Care. (2012). End Stage Renal Disease patients in 2011: A Global Perspective. Retrieved from http://www.vision-fmc.com/files/dc.

Fresenius Medical Care South Africa (2008). Fresenius Medical Care Annual Report 2008. Retrieved from http://reports.fmcag.com/reports/fmc/annual/2008/gb/English/8030/major-subsidiaries.html.

Furr, L.A. (1998). Psycho-social aspects of serious renal disease: A review of the literature. *Social Work in Health Care, 27* (3), 97-118.

Gerrish, K., & Lacey, A (2006). *The research process in nursing* (5th ed.). Australia: Blackwell Publishing Ltd.

Ginieri-Coccossis, M., Theofilou, P., Synodinou, C., Tomaras, V., & Soldatos, C. (2008). Quality of life, mental health and health beliefs in haemodialysis and peritoneal dialysis patients: Investigating differences in early and later years of current treatment. *Biomedcentral Nephrology, 9,* Article 14. Retrieved from http://www.biomedcentral.com/1471-2369/9/14. doi:10.1186/1471-2369-9-14

Giles, S. (2003). Transformations: a phenomenological investigation into the life-world of home haemodialysis. *Social Work in Health Care, 38* (2), 29-50.

Gillis, A., & Jackson, W. (2002). *Research for Nurses: Methods and interpretation* (1st ed.). Philadelphia: F. A. Davis Company.

Hagren, B., Pettersen, I.M., Severinsson, E., Lutzen, K., & Clyne, N. (2001). The haemodialysis machine as a lifeline: experiences of suffering from end-stage renal disease. *Journal of Advanced Nursing, 34* (2), 196–202.

Hagren, B., Pettersen, I.M., Severinsson, E., Lutzen, K., & Clyne, N. (2005). Maintenance haemodialysis: patients' experiences of their life situation. *Journal of Clinical Nursing, 14* (3), 294–300.

Hartley, S., & Muhit, M. (2003). Using qualitative research methods for disability research in majority world countries. *Asia Pacific Disability Rehabilitation Journal, 14* (2), 103-113. Retrieved from http://english.aifo.it/disability/apdrj/apdrj203/qualitative-research.pdf

Hatch, J. A. (2002). Doing Qualitative Research in Education Setting. State University of New York Press.

Hedayati, S.S, Yalamanchili, V., & Finkelstein, F.O. (2012). A practical approach to the treatment of depression in patients with chronic kidney disease and end-stage renal disease. *Kidney International, 81*(3), 247-255. doi: 10.1038/ki.2011.358.

Heiwe S., Clyne N., & Dalhgren M.A. (2003). Living with chronic renal failure: patients' experiences of their physical and functional capacity. *Physiotherapy Research International, 8*(4), 167-177.

Herlin, C., & Wann-Hasson, C. (2010). The experience of being 30-45 years of age and depending on haemodialysis treatment: a phenomenological study. *Scandinavian Journal of Caring Science, 24*(4), 693-699. doi: 10.1111/j.1471-6712.2009.00764.x.

Himmelfarb, J. (2005). Core Curriculum in Nephrology: Haemodialysis complications. *American Journal of Kidney Diseases, 5* (6), 1122-1131.

Holloway, I., & Wheeler, S. (2010). *Qualitative Research in Nursing and Healthcare* (3rd ed.). Wiley-Blackwell.

Jansen, D. L., Rijkena, M., Heijmansa, M., & Boeschotenby, E.W. (2010). Perceived autonomy and self-esteem in Dutch dialysis patients: The importance of illness and treatment perceptions. *Journal of Psychology and Health, 25*(6), 733-749.

Kaba E., Bellou P., Iordanou P., Andrea S., Kyritsi E., Gerogianni G., Zetta S., & Swigart V. (2007). Problems experienced by haemodialysis patients in Greece. *British Journal of Nursing, 16*(14), 868–872.

Karamanidou, C., Theofilou, P., Ginieri-Coccossis, M., Synodinou, C., & Papadimitriou, G. (2009). Anxiety, depression and health beliefs in end-stage renal disease (ESRD) patients. *European Psychiatry, 24*(1), 651. doi:10.1016/S0924-9338(09)70884-3.

Kastrouni, M., Sarantopoulou, E., Aperis, G., & Alivanis, P. (2010). Quality of life of Greek patients with end stage renal disease undergoing haemodialysis. *Journal of Renal Care, 36* (3), 26-132. doi: 10.1111/j.1755-6686.2010.00187.x.

Keil, R.M.K. (2004). Coping and stress: a conceptual analysis. *Journal Advance Nursing, 45* (6), 659-665.

Kessler, R.C., Berglund, P., & Demler, O., Jin, R., Koretz, D., Merikangas, K.R., … & Wang, P.S. (2003). The epidemiology of major depressive disorder: results from the National Comorbidity Survey Replication (NCS-R). *Journal of the American Medical Association, 289* (23), 3095–3105.

Khalil, A.A., & Frazier, S.K. (2010). Depressive symptoms and dietary nonadherence in patients with end-stage renal disease receiving hemodialysis: a review of quantitative evidence. *Issues in Mental Health Nursing, 31*(5), 324-30.

Kimmel, P.L, & Peterson, R.A. (2006). Depression in patients with end-stage renal disease treated with dialysis: Has the time to treat arrived*? Clinical Journal of the American Society of Nephrology*, *1*(3), 349-352.

Kimmel, P.L., Cukor, D., Cohen, S.D., & Peterson, R.A. (2007). Depression in end-stage renal disease patients: A critical review. *Advances in Chronic Kidney Disease*, *14*(4), 328-334.

Klang, B., Bjorvell, H., & Clyne, N. (1999). Predialysis education helps patients choose dialysis modality and increases disease – specific knowledge. *Journal of Advanced Nursing, 29* (4), 869- 876.

Ko, F.C., Lee, B.O., & Shih, H.T. (2007). Subjective quality of life in patients undergoing long-term maintenance haemodialysis treatment: A qualitative perspective. Hu Li Za Zhi 54(1), 53-61 (original article in Chinese). Retrieved from http://www.ncbi.nlm.nih.gov/pubmed.

Koch, T. (2006). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing 53*(1), 91-103.

Kohli, S., Batra, P. & Aggarwal, H.K. (2011). Anxiety, locus of control, and coping strategies among end-stage renal disease patients undergoing maintenance hemodialysis. *Indian Journal of Nephrology, 21*(3), 177-181.

Krueger, L. (2009) Experiences of Hmong patients on hemodialysis and the nurses working with them. *Nephrology Nursing Journal, 36*(4), 379–387.

Krzanowski, M., Janda, K., Chowaniec, E., & Sułowicz, W. (2011). Hemodialysis vascular access infection and mortality in maintenance hemodialysis patients. *Przeglad, lekarski, 68* (12), 1157-1161.

Laupacis, A., Keown, P., Pus, N., Krueger, H., Ferguson, B., Wong, C., & Muirhead, N. (1996). A study of the quality of life and cost-utility of renal transplantation. *Kidney International, 50* (1), 235-420.

Lazarus, R.S., & Folkman, S. (1984). Stress, Appraisal and Coping. Springer, New York, USA.

Lee, B.O., Lin, C.C., Chaboyer, W., Chiang, C.L., & Hung, C.C. (2007). The fatigue experience of haemodialysis patients in Taiwan. *Journal of Clinical Nursing, 16*(2), 407–413.

Lii, Y., Tsay, S., & Wang, T. (2007). Group intervention to improve quality of life in haemodialysis patients. *Journal Clinical Nursing, 16* (11C), 268-275.

Lim, Y.N., Ong, L.M., & Goh, B.L. (2012). Nineteenth Report of the Malaysian Dialysis and Transplant Registry 2011. Kuala Lumpur. Retrieved from http://www.msn.org.my/nrr.

Lincoln, Y.S., & Guba, E.A. (1985). *Naturalistic inquiry*. Sage, Beverly Hills, CA.

Lindquist, R., Carlsson, M., & Sjoden, P. (2000). Perceived consequences of being a renal failure patient. *Nephrology Nursing Journal, 27*(3), 291-298.

Logan, S.M., Pelletier-Hibbert, M. & Hodgins, M. (2006). Stressors and coping of in-hospital haemodialysis patients aged 65 years and over. *Journal of Advanced Nursing*, *56*(4):382-91.

Lok, P. (1996). Stressors, coping mechanisms and quality of life among dialysis patients in Australia. *Journal of Advanced Nursing, 23*(5), 873-88.

Louis, F.S. (2010). Quality-of-life experiences from the perspective of patients receiving haemodialysis for chronic renal failure. *Health SA Gesondheid, 15*(1), 187.

Malaysian Organ Sharing System (2013). National Kidney Organ Waiting List. Retrieved on from https://www.macr.org.my/emoss/RRU_login.jsp.

Marshall, C., & Rossman, G.B. (2006). *Designing qualitative research.* (4th ed.). New Delhi: Sage Publications.

Martin-McDonald, K. (2003). Being dialysis-dependent: a qualitative perspective. *Royal College of Nursing, Australia, 10* (2), 29-33.

Martin-McDonald, K. (2004). Dialysis-dependency: the reformulated or remnant person. *Contemporary Nurse, 16*(1–2), 151-160.

McCann, K., & Boore J.R.P. (2000). Fatigue in persons with renal failure who require maintenance haemodialysis. *Journal of Advanced Nursing, 32*(5), 1132–1142.

Merriam, S.B. (2002). *Introduction to Qualitative Research*. Retrieved from http://stu.westga.edu/~bthibau1/MEDT%208484-%20Baylen/introduction_to_qualitative_research/introduction_to_qualitative_research.pdf.

Mitchell, A., Farrand, P., James H., Luke R., & Wyatt, K. (2009). Patients' experience of transition onto haemodialysis: a qualitative study. *Journal of Renal Care, 35*(2), 99-107.

Mok, E., & Tam, B. (2001). Stressors and coping methods among chronic haemodialysis patients in Hong Kong. *Journal of Clinical Nursing, 10*(4), 503–511

Molzahn, A., Bruce, A., & Shields, L. (2008). Learning from stories of people with chronic kidney disease. *Nephrology Nursing Journal, 35*(1), 13-20.

Moosa, M. R., Naicker, S., Naiker, I., Pascoe, M., & van Rensberg, B. (2006). Guidelines for the optimal care of patients on chronic dialysis in South Africa. Retrieved from South African Renal Society website: http://www.kznhealth.gov.za/medicine/sars.pdf

Moran, A., Scott, A., & Darbyshire, P. (2010). Waiting for a kidney transplant: patients' experiences of haemodialysis therapy. *Journal of Advanced Nursing, 67*(3), 501-509.

Morse, J.M., & Field, P.A. (1996). *Nursing Research: The Application of Qualitative Approaches* (2nd ed.). Chapman & Hall, London.

Moules, N.J. (2002). Hermeneutic inquiry: Paying heed history and hermes – An ancestral, substantive, and methodological tale. *International Journal of Qualitative Methods 1* (3), Article 1. Retrieved from http://www.ualberta.ca/-ijqm.

Mucsi, I, Kovacs, A.Z, Molnar, M.Z., Novak, M. (2008). Comorbidity and quality of life in chronic kidney disease patients. *Journal Nephrology, 21* (13), 84-91.

Muehrer, R.J., Schatell, D., Witten, B., Gangnon, R., Becker, B., & Michael Hofmann, R. (2011). Factors Affecting Employment at Initiation of Dialysis. *Clinical Journal of the American Society of Nephrology, 6*(3), 489-496.

Muringai, T., Nobele, H.,McGowan, A., & Chamney, M. (2008). Dialysis access and the impact on body image: role of the nephrology nurse. *British Journal of Nursing, 17*(6), 362-366.

Murtagh, F.E., Addington-Hall, J., & Higginson, I.J. (2007). The prevalence of symptoms in end-stage renal disease: a systematic review. *Advances in Chronic Kidney Disease, 14*(1), 82-99.

National Kidney Foundation (2002). K/DOQI clinical practice guidelines for chronic kidney disease evaluation, classification, and stratification. Retrieved from http://www2.kidney.org/professionals/KDOQI/guidelines_ckd/p4_class_g1.htm.

National Kidney Foundation (2005). A to Z health guide: Dialysis. Retrieved from http://www.kidney.org/atoz/content/dialysisinfo.

Patton, M.Q (2002). *Qualitative Research & Evaluation Methods*. (3rd ed.). Sage. London. ISBN: 0761919716.

Polaschek, N. (2003). The experience of living on dialysis: A literature review. *Nephrology Nurses Journal, 30*(3), 303-313.

Polit, D. F. & Beck, C.T (2006). *Essential of nursing research: Methods, Appraisal, and Utilization* (6th ed.). Lippincott Williams & Wilkins. Philadelphia PA.

Polner, K., Szeifert, L., Vámos, E.P., Ambrus, C., Molnár, M.Z., Ladányi, E., ... & Turi, S. (2011). Psychosocial characteristics and self-reported functional status in patients on maintenance dialysis in Hungary. *Clinical Nephrology, 76*(6), 455-463.

Reichsman, F., & Levy, N. (1972). Problems in Adaptation to Maintenance Hemodialysis: A Four-Year Study of 25 Patients. *Archieve International Medicine, 130*(6), 859-865.

Rittman, M., Northsea, C., Hausauer, N., Green, C., & Swanson, L. (1993). Living with renal failure. *American Nephrology Nurse Association Journal, 20*(3), 327-332.

Ronco, C., Davenport, A., & Gura, V. (2011). The future of the artificial kidney: moving towards wearable and miniaturized devices. *Nefrologia; 31*(1), 9-16.

Saeed, Z., Ahmad, A.M., Shakoor, A., Ghafoor, F., & Kanwal, S. (2012). Depression in patients on hemodialysis and their caregivers. *Saudi Journal of Kidney Diseases and*

Transplantation, 23(5), 946-952. doi: 10.4103/1319-2442.100869.

Sadala, M.L.A., & Lorencon, M. (2006). Living with a haemodialysis machine. *Journal of Renal Care, 32*(3), 147-152.

Sarawak General Hospital (2012). Statistics of haemodialysis patients in Sarawak in 2011. Unpublished data.

Sarawak State Health Department (2012). *Heritage in Health: The story of Medical and Health Care Services in Sarawak*. Kuching, Sarawak

Scaife, T. D. (2006). What is the Lived Experience of the Client with End Stage Renal Disease On Haemodialysis. Retrieved from http://utdr.utoledo.edu/cgi/viewcontent.cgi?article=2403&context=theses-dissertations.

Sensky, T. (1993). Psychosomatic aspects of end-stage renal failure. *Psychotherapy and Psychosomatics, 59*(2), 56–68.

Shih, L.C, & Honey, M. (2011). The impact of dialysis on rurally based Maori and their whänau/families. *Nursing Praxis in New Zealand, 27*(2), 4-15.

Smith, S., & Soliday, E. (2001). The effects of parental chronic kidney disease on the family. *Family Relations, 50*(2), 171-177.

Sousa, A.D. (2008). Psychiatric issues in renal failure and dialysis. *India Journal of Nephrology, 18*(2), 47-50.

Speziale, H.J.S., & Carpenter, D.R. (2007). *Qualitative research in Nursing: Advancing the humanistic imperative* (4th ed.). Lippincott Williams & Wilkins.

Suet-Ching, W.L. (2001). The quality of life for Hong Kong dialysis patients. *Journal of Advanced Nursing*, *35*(2), 218-227.

Tanyi, R., & Werner, J. (2008). Toward a trajectory of adjustment in women with end-stage renal disease. *Journal of Clinical Nursing*, *17*(5a), 43–50.

Theofilou, P. (2011e). Noncompliance with medical regimen in haemodialysis treatment: A case study. *Case Reports in Nephrology, Volume 2011,* Article ID 476038. doi:10.1155/2011/476038

Theofilou, P. (2012). Quality of life and mental health in hemodialysis and peritoneal dialysis patients: The role of health beliefs. *International Urology and Nephrology*, *44*(1), 245-253.

Theofilou, P. (2012e). The relation of social support to mental health and locus of control in chronic kidney disease. *Journal of Renal Nursing, 4*(1), 18-22.

Theofilou, P., Synodinoua, C., & Panagiotakic, H. (2013). Undergoing Haemodialysis: A Qualitative Study to Investigate the Lived Experiences of Patients. *Europe's Journal of Psychology*, *9*(1), 19.

Thomas, N.T. (2002). *Renal Nursing*.(2nd ed.). Baiilière Tindall. London.

Thomas, N. (2004). Care and management of diabetic nephropathy (Moderate to advanced renal involvement . *Journal of Renal Care, 30*(3), 120-123. doi: 10.1111/j.1755-6686.2004.tb00348.x

Tobin, G.A., & Begley, C.M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388-396.

Tong, A., Sainsbury, P., Chadban, S., Walker, R., Harris, D., Carter, S, & Hall, B. (2009). Patients' experiences and perspectives of living with CKD. *American Journal of Kidney Diseases, 53*(4), 689-700.

United State Renal Data System (2005). USRDS Annual Report [Electronic version]. Bethesda, MD: National Institute of Health. National Institute of Diabetes and Digestive and Kidney Diseases. Retrieved from http://www.usrds.org/reference.htm

Van Manen, J.G., Korevaar, J.C., Dekker, F.W., Reuselaars, M.C., Boescholen, E.N., Krediet, R.T., & The NECOSAD Study Group (2001). Changes in employment status in end-stage renal disease patients during the first year of dialysis. *Peritoneal Dialysis International, 21*(6), 595-601.

Wadd, K., King L., Bennett P., & Grant J. (2011). Being a parent on dialysis: a literature review. *Journal of Renal Care*, *37*(4), 208-215.

Waddel, G., & Burton, A.K. (2006). *Is work good for your health and wellbeing ?* London: The Stationery Office.

Weaver, K., & Olson, J.K, (2006). Understanding paradigms used for nursing research. *Journal of Avanced Nursing, 53*(5), 459-469.

Weisbord, S. D., Fried, L. F., Arnold, R. M., Fine, M. J., Levenson, D. J., Peterson, R. A., & Switzer, G. E. (2005). Prevalence, severity, and importance of physical and emotional symptoms in chronic hemodialysis patients. *Journal of the American Society of Nephrology, 16*(8), 2487-2494.

Welch, J.L, & Austin, J.K. (2001). Stressors, coping and depression in haemodialysis patients. *Journal of Advanced Nursing, 33*(2), 200-207.

Wolcott, D. L., Maida, C. A., Diamond, R., & Nissenson, A. R. (1986). Treatment compliance in end-stage renal disease patients on dialysis. *American Journal of Nephrology, 6*(5), 329-338.

Yodchai, K., Dunning, T., Hutchinson, A.M., Oumtanee, A., & Savage, S. (2011). How do Thai patients with end stage renal disease adapt to being dependent on haemodialysis? A pilot study. *Journal of Renal Care, 37*(4), 216-223.

Yeh, S.C., & Chou, H.C. (2007). Coping strategies and stressors in patients with hemodialysis. *Psychosomatic Medicine, 69*(2), 182-190.

Zabidah, P. (2010). *Domestic Violence: Towards a better exit*. *Reaching abused women to redefine themselves, directions and life*. Germancy: LAP LAMBERT Academic.

APPENDICES

Appendix A

Fakulti Perubatan dan Sains Kesihatan
Faculty of Medicine and Health Sciences

UNIVERSITI MALAYSIA SARAWAK

Lot 77, Seksyen 22
Kuching Town Land District
Jalan Tun Ahmad Zaidi Adruce
93150 Kuching, Sarawak
Tel + 60 82 416550
Fax + 60 82 422564
www.unimas.my

UNIMAS/TNC(AA)-03.02/06-11 Jld. 2(13)

17 April 2012

Lau Sie Ngo
Fakulti Perubatan dan Sains Kesihatan
Universiti Malaysia Sarawak
Lot 77, Seksyen 22, Jalan Tun Ahmad Zaidi Adruce
93150 Kuching

Puan

Keputusan Kertas Kerja Penyelidikan
- ***Experiences of Renal Failure Patients Living on Haemodialysis***

Dengan segala hormatnya perkara di atas dirujuk.

Sukacita dimaklumkan bahawa kertas kerja penyelidikan seperti di atas yang dijalankan oleh Lau Sie Ngo telah **diluluskan** pada Mesyuarat Jawatankuasa Penyelidikan dan Etika Fakulti bil 1/2012 pada 7 Mac 2012 yang lalu.

Sehubungan itu, penyelidikan tersebut boleh dijalankan bermula dari tarikh surat ini seperti di atas.

Sekian, terima kasih.

Tan Sri Datu Prof. Dr. Mohamad Taha Arif
Pengerusi
Jawatankuasa Etika Perubatan
Fakulti Perubatan dan Sains Kesihatan

s.k. Timbalan Dekan
Pascasiswazah dan Penyelidikan
Fakulti Perubatan dan Sains Kesihatan

Da/Etika/Keluluscan

MSC-Status

Appendix B

NATIONAL INSTITUTES OF HEALTH APPROVAL FOR CONDUCTING RESEARCH IN THE MINISTRY OF HEALTH MALAYSIA

PENGESAHAN INSTITUSI PENYELIDIKAN NEGARA UNTUK MENJALANKAN PENYELIDIKAN DI KEMENTERIAN KESIHATAN

This is an auto computer - generated document. It is issued by one of the research institute under the National Institutes of Health (NIH). These are the Institute for Medical Research (IMR), Clinical Research Centre (CRC), Institute for Public Health (IPH), Institute for Health Management (IHM), Institute for Health Systems Research (IHSR), and Institute for Health Behavioural Research (IHBR)

Dokumen ini adalah cetakan berkomputer. Borang ini dikeluarkan oleh salah satu institusi dibawah National Institutes of Health (NIH) iaitu Institut Pen yelidikan Perubatan (1MR), Pusat Pen yelidikan Klinikal (CRC), Institut Kesihatan Umum (WU), Institut Pen gurusan Kesihatan (IPK), Institut Pergurusan Sistem Kesihatan (1PSK), Institut Penyelidikan Tin gkahlaku Kesihatan (1PTK)

Unique NMRR Registration ID: [Nombor Pendaftaran]	NMRR-12-138-11505
Research Title : [Tajuk]	Experiences of Renal Failure Patients Living on Haernodialysis
Protocol Number if available : [Nombor Protokol jika ada]	

#	**Investigator Name [Name Penyelidik]**	**Institution Name [Nama Institusi)**
1	Lau Sie Ngo	Sarawak General Hospital

I have reviewed the above titled research, and approve of its design and conduct.

Saya telah menyemak kajian yang bertajuk Seperti di etas dan meluluskan rekabentuk dan perlaksanaannya.

Name of Director : *'Mama Penciarah]*	Dr. Goh Pik Pin
NIH Institute (IMR, CRC, IPH, IHM, IHSR and IHBR) *[Nama lnstitusi di bawah MIN*	Clinical Research Centre (CRC)
Signature & Official stamp : *[Tandatangan dan Cop Rasmi]*	This is computer generated document, therefore no signature is required.
Date : *[Tarikh]*	26-03-2012

(Note: This is a computer generated document. It may not carry any signature)

Appendix C: A sample to seek permission to recruit participant from private and NGO Haemodialysis Center

Lau Sie Ngo,

Penyelia Jururawat U42,

Haemodialysis Unit,

Hospital Umum Sarawak,

Kuching, Sarawak.

Board of Management,

Pusat Dialisis Cahaya,

Kuching, Sarawak. 23.03.2012

Tuan,

Memohon Kebenaran untuk Menjemput Pesakit Hemodialisis Menyertai Kajian

Dengan hormatnya perkara di atas adalah dirujuk.

2. Saya, Lau Sie Ngo, No matrik: 11021697 adalah pelajar Sarjana Kejururawatan, Fakulti Perubatan dan Sains Kesihatan, Universiti Malaysia Sarawak. Saya ingin memohon kebenaran daripada pihak tuan/puan untuk menjemput pesakit-pesakit yang memerima rawatan hemodialisis di pusat hemodialisis tuan untuk menyertai dalam kajian berikut:

Tajuk Kajian: Experiences of Renal Failure Patients Living on Haemodialysis

Penyelia Kajian: Associate Professor Dr. Zabidah Binti Putit dan Cik Jane Buncuan

3. Pesakit-pesakit hemodialisis yang menyertai kajian ini akan ditemubual untuk memberitahu pengalaman hidup dengan rawatan hemodialisis. Kajian ini tidak melibatkan apa-apa prosedur. Identiti pesakit dan segala maklumat yang diberitahu adalah sulit dan tidak akan didedahkan kepada sesiapa kecuali penyelidik dan penyelia kajian ini. Kajian ini telah disemak dan diluluskan oleh komiti penyelidikan Faculty Medicine and Health Science, UNIMAS dan"Medical Research Ethics Committee", Kementerian Kesihatan Malaysia.

4. Segala perhatian dan pertimbangan dari pihak tuan amatlah dihargai dan didahului dengan ucapan ribuan terima kasih. Sekian, terima kasih.

Yang benar,

Lau Sie Ngo (No. Tel: 016-8714338)

Appendix D: Permission of the Hospital Director and Head of Department of Haemodialysis Unit at Sarawak General Hospital

Versi 2.0 Tarikh: 15 Feb 2012

INVESTIGATOR'S AGREEMENT, HEAD OF DEPARTMENT'S AND INSTITUTIONAL APPROVAL

PERSETUJUAN PENYELIDIK, PENGESAHAN KETUA JABATAN DAN INSTITUSI

This document is intended for online submission for purpose of formal research review and approval. It is to be used *in lieu* of other equivalent manually printed document such as Borang JTP/KKM 1-2 and Borang JTP/KKM 3. After completing the form below and obtaining the required signatures, please scan this document and submit online.

Dokumen ini adalah untuk penghantaraan atas talian (online) mengikut prosedur rasmi semakan dan persetujuan penyelidikan. Borang ini dikeluarkan sebagai gantian dokumen kebenaran manual yang serupa seperti Borang JTP/KKM 1-2 dan Borang JTP/KKM 3. Selepas melengkapkan borang di bawah dan mendapatkan tanda tangan yang diperlukan, sila imbaskan dokumen ini dan hantar atas talian.

Research Title: *[Tajuk Penyelidikan]*	Experiences of Renal Failure Patients Living on Haemodialysis
Protocol Number if available: *[Nombor Protokol jika ada]*	

Investigator agreement *[Persetujuan penyelidik]*

I have understood the above titled proposed research and I agree to participate in the research as an investigator.

Saya faham cadangan penyelidikan yang bertajuk di atas dan saya bersetuju mengambil bahagian dalam projek tersebut sebagai penyelidik

Name of Investigator *[Nama Penyelidik]*	Lau Sie Ngo
IC number *[Nombor KP]*	690813-13-5078
Institution *[Institusi]*	Hospital Umum Sarawak / University Malaysia Sarawak
Signature & Official stamp *[Tandatangan dan Cop Rasmi]*	LAU SIE NGO JURURAWAT U42 NO. LJM: 27867
Date *[Tarikh]*	14/03/2012

Head of Department Agreement *[Persetujuan Ketua Jabatan]*

I agree to allow the above named investigator to conduct or to participate in the above titled research

Saya membenarkan pegawai yang bernama di atas untuk menjadi penyelidik dalam projek penyelidikan tersebut di atas.

Name of Head *[Nama Ketua]*	DR CLARE TAN HUI HONG
Name of Department and Institution *[Jabatan dan Institusi]*	Nephrology Unit Hospital Umum Sarawak
Signature & Official stamp *[Tandatangan dan Cop Rasmi]*	DR CLARE TAN HUI HONG
Date *[Tarikh]*	14/3/2012

Institutional approval *[Pengesahan Institusi]*

This section maybe omitted if one of the NIH institute is authorized to approve on behalf of institution. Refer NIH for details *[Bahagian ini tidak perlu jika salah satu daripada institusi NIH diberi kuasa pengesahan bagi pihak institusi tersebut. Rujuk NIH untuk maklumat lanjut]*

I agree to allow the investigator(s) named above to conduct or to participate in the above titled research. Where applicable, I further agree to allow my institution to be one of the sites participating in the research.

Saya membenarkan pegawai yang bernama di atas menjalankan penyelidikan selaku penyelidik dalam projek penyelidikan tersebut. Jika berkenaan, saya juga membenarkan institusi ini mengambil bahagian dalam projek tersebut.

Name of Director *[Nama pengarah]*	DR. ABDUL RAHIM B. ABDULLAH
Name of Institution *[Nama Institusi]*	PENGARAH HOSPITAL UMUM SARAWAK MMC NO: 25483
Signature & Official stamp *[Tandatangan dan Cop Rasmi]*	
Date *[Tarikh]*	14/3/12

Appendix E: Permission from board of management of Renal Life Dialysis Centre

Renal Life Dialysis Centre Sdn Bhd

Mdm Lau Sie Ngo,
Penyelia Jururawat U42 Haemodialysis Unit
HUS
Kuching **23/04/2013**

Dear Matron Lau,

Re: Acceptance of Request for study purposes

This serves to inform that the management has granted you permission with regards to the above mentioned as requested by you.

However we would to request for your trust in our clients' personal and medical records are to be kept confidential.

Thank you.

Regards.

Regards,

Sr Rose M W Ho
Manager
Renal Life Dialysis Centre Sdn Bhd

Lot 2479, Ground Floor, Fortune Land Business Centre, Jalan Rock Mile 2¼, 93200 Kuching.
Tel: 082 422144 Fax: 082 252144 Email: rhomw01@yahoo.com

Lot 2479, Ground Floor, Fortune Land Business Centre, Jalan Rock Mile 2¼, 93200 Kuching.
Tel: 082 422144 Fax: 082 252144 Email: rhomw01@yahoo.com

Appendix F: Permission from board of management of Pusat Dialysis Cahaya

PUSAT DIALISIS CAHAYA

Lot 211, Ground Floor, Jalan Haji Taha, 93400 Kuching

Phone: 082 425735 Fax: 082 4257

30th May 2013

Lau Sie Ngo

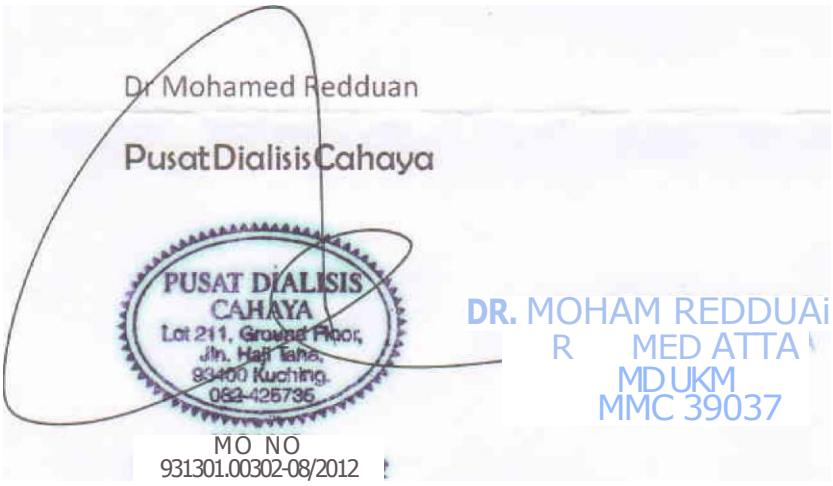
Haemodialysis Unit

Hospital Umum Sarawak

Kebenaran untuk menjemput pesakit hemodialysis meyertai kajian

Dengan hormatnya saya merujuk kepada surat puan bertarikh 23 March 2012. **Dengan ini sukacitanya saya member kebenaran tersebut untuk tujuan kajian pihak puan.**

Yang Benar,



Appendix G: Permission from board of management of KAS-Rotary-National Kidney Foundation of Malaysia

Foundation of Malaysia

[redacted]/2012 10:58 HP LASERJET FAX

Attn: Mr Tan (SDM)

Lau Sie Ngo,
Penyelia Jururawat U42,
Haemodialysis Unit,
Hospital Umum Sarawak,
Kuching, Sarawak.

KAS-ROTARY-NKF DIALYSIS CENTRE
KUCHING
RECEIVED 14/5/2012 @ 10.25 am
DATE:

Refax to: Mr Tan SDM.

Board of Management,
National Kidney Foundation Dialysis Centre,
Kuching, Sarawak.

23.03.2012

Tuan,

Memohon Kebenaran untuk Menjemput Pesakit Hemodialisis Menyertai Kajian

Dengan hormatnya perkara di atas adalah dirujuk.

2. Saya, Lau Sie Ngo, No matrik: 11021697 adalah pelajar Sarjana Kejururawatan, Fakulti Perubatan dan Sains Kesihatan, Universiti Malaysia Sarawak. Saya ingin memohon kebenaran daripada pihak tuan/puan untuk menjemput pesakit-pesakit yang menerima rawatan hemodialisis di pusat hemodialisis tuan untuk menyertai dalam kajian berikut:

Tajuk Kajian: "Experiences of Renal Failure Patients Living on Haemodialysis

Penyelia Kajian: Dr. Zabidah Binti Putit dan Cik Jane Buncuan

3. Pesakit-pesakit hemodialisis yang menyertai kajian ini akan ditemubual untuk memberitahu pengalaman hidup dengan rawatan hemodialisis. Kajian ini tidak melibatkan apa-apa prosedur. Identiti pesakit dan segala maklumat yang diberitahu adalah sulit dan tidak akan didedahkan kepada sesiapa kecuali penyelidik dan penyelia kajian ini. Kajian ini telah disemak dan diluluskan oleh komiti penyelidikan Faculty Medicine and Health Science, UNIMAS dan "Medical Research Ethics Committee", Kementerian Kesihatan Malaysia.

4. Segala perhatian dan pertimbangan dari pihak tuan amatlah dihargai dan didahului dengan ucapan ribuan terima kasih.

Sekian, terima kasih.

Yang benar,

Lau

Lau Sie Ngo
No. Tel: 016-8714338
Siengolau@gmail.com

NATIONAL KIDNEY FOUNDATION MALAYSIA
MEDICAL
14 MAY 2012

Sokong -

TAN CHOR SEONG AMP.
Senior Dialysis Manager
National Kidney Foundation of Malaysia

14/05 2012 10:27 FAX 421826

001

Appendix H : Participant Information Sheet & Informed Consent Form (English version)

Fakulti Perubatan dan Sains Kesihatan
Universiti Malaysia Sarawak

PARTICIPANT'S INFORMATION SHEET & INFORMED CONSENT FORM (ENGLISH VERSION)

A: PARTICIPANT'S INFORMATION SHEET

PROTOCOL TITLE

Experiences of Patients with End Stage Renal Disease Living on Haemodialysis.

PRINCIPAL INVESTIGATOR:

Lau Sie Ngo, student of Master of Science (Nursing), Universiti Malaysia Sarawak.

SUPERVISOR

Associate Professor Dr. Zabidah Bt. Putit and Miss Jane Buncuan

INSTITUTION ADDRESS

Faculty of Medicine and Health Sciences, Universiti Malaysia Sarawak, Lot 77, Section 22 Kuching Town Land District, Jalan Tun Ahmad Zaidi Adruce, 93150 Kuching, Sarawak, Malaysia.

THE NATURE AND PURPOSE OF THE STUDY

The purpose of this study is to explore the lived experience of people suffering from ESRD and life depending on HD treatment in public and community Haemodialysis Unit in Kuching.

STUDY DESCRIPTION

This study aimed to explore the real-life experience of ESRD patients living on HD in Kuching. End stage renal disease patients on Haemodialysis treatment, aged between 18 to 65 years and meet all the inclusion criteria will be recruited as the participants of this study. The data will be collected by researcher alone. A participate will be interviewed for about 60 to 90 mi nutes through 1 to 2 sessions of semi-structured interview with the help of an interview guide. The interview will be audio-taped.

RISK OF STUDY PARTICIPANTION

This study will not require any invasive procedures. There are no significant risks.

POSSIBLE BENEFITS OF STUDY PARTICIPATION

This study is on a voluntary basis. The potential benefits of participating in this study are that you can increase your knowledge about your condition and satisfaction that the information you provide may help others with the similar situation. Besides that, the result and information from this study may be useful in the development of effective educational programs in preparing the nurses for their role in dealing with patients living on haemodialysis. In addition, this study would also help to identify the areas that could be used in modification of the future curriculum.

WITHDRAWAL FROM STUDY

You have the right to withdraw or quit from the study at any time without penalty.

TO OBTAIN FURTHER INFORMATION

If you need further information or clarification, you can contact the researcher via email at siengolau@gmail.com or telephone number (016-8714338).

VOLUNTARY PARTICIPATION

Your participation in this study is voluntary where you have the right to refuse and not force to participate. You must inform the researcher of this decision immediately.

CONFIDENTIALTY

For your information, your name and information collected from the participant is only confiding to the researcher and her supervisor. Only the researcher knows the participant real name and contact address. Participant anonymity will be kept confidential as only pseudonym will be used. Any names of the people and the institution or organizations mention in the interview will be kept confidential as well. Your clinical information obtained for the purpose of this study will remain confidential and it will not be possible to identify the names or individual details of any study participant based on any publication or presentation arising from this study. The recorded tape and transcript will be kept in a safeguarded place. Only the researcher and her supervisor will read the transcript.

Thanks you for considering this request to participate in this study.

Sincerely,

_____

[Lau Sie Ngo]

Note:

1. This study is being conducted by: Researcher(s) name, designation, institution's address

2. This study has been reviewed and approved by the Medical Research & Ethics Committee, Ministry of Health Malaysia. This committee is responsible for reviewing and approving any research project that involve patients or public.

B: INFORMED **CONSENT FORM FOR RESEARCH PROJECT:**

EXPERIENCES OF RENAL FAILURE PATIENTS LIVING ON HAEMODIALYSIS

I _____ (NRIC:_____) hereby voluntarily consent and confirm I will take part in the above study. By signing this Consent Form, I further confirm the following:-

1. I confirm that I have read or have had read to me in language understandable to me and understand the information letter for the above study and have had the opportunity to ask questions.
2. I understand that this participation is voluntary and that I am free to withdraw at any time without giving any reason and my medical care will not be affected by this.
3. I understand and agree that the study results may be presented in an academic conference or published in a journal article, but all personal names and any other identifying information will not be revealed in anyway. All personal details will be kept at the strictest of confidence.

Participant	**Witness**
Signature:_____	Signature:_____
Name :_____	Name :_____
IC No.:_____	IC No:_____
Date:_____	Date:_____

Declaration by researcher: I have given a verbal explanation of the research project and I believe that the participant has understood that explanation.

Researcher

Signature:_____

Name:_____

IC No.:_____

Date:_____

Appendix I: Participant Information Sheet & Informed Consent Form (Malay version)

Fakulti Perubatan dan Sains Kesihatan
Universiti Malaysia Sarawak

MAKLUMAT MENGENAI KAJIAN UNTUK PESERTA DAN

SURAT KEBENARAN

A: MAKLUMAT MENGENAI KAJIAN UNTUK PESERTA

TAJUK KAJIAN

Pengalaman Pesakit Kegagalan Buah Pinggang Peringkat Akhir Hidup dengan Hemodialisis.

PENYELIDIK

Lau Sie Ngo, pelajar Sarjana Sains Kejururawatan, Universiti Malaysia Sarawak.

PENYELIA

Associate Professor Dr. Zabidah Bt Putit dan Cik Jane Buncuan

ALAMAT INSTITUSI

Fakulti Perubatan dan Sains Kesihatan, Universiti Malaysia Sarawak, Lot 77, Section 22 Kuching Town Land District, Jalan Tun Ahmad Zaidi Adruce, 93150 kuching, Sarawak, Malaysia.

TUJUAN KAJIAN

Tujuan utama kajian ini ialah untuk mengetahui pengalaman pesakit menghidapi kegagalan buah pinggng peringkat akhir dan hehidupan bergantung kepada rawatan hemodialisis yang tinggal di Kuching, Sarawak. Maklumat yang diberi akan berfaedah kepada organisasi kesihatan untuk memberi rawatan dan jagaan kepada pesakit dialisis dan juga orang awam. Kami berharap dapat mengesan kelemahan dari segi kesefahaman supaya dapat membuat penambahbaikan.

PENJELASAN TENTANG KAJIAN

Kajian ini bertujuan untuk mengetahui pengalaman pesakit yang menghidapi Kegagalan Buah Pinggang Peringkat Akhir dan kehidupan bergantug kepada rawatan hemodialisi yang tinggal di Kuching, Sarawak. Pesakit yang berumur di antara 18 hingga 65 tahun dan memenuhi kriteria yang telah ditetapkan akan dipilih untuk menyertai kajian ini. Maklumat akan dikumpul oleh penyelidik sendiri. Tuan /Puan akan ditemuramal melalui satu hingga dua sesi temubual pada hari yang berlainan selama 60 hingga 90 minit setiap sesi di bilik kaunseling, Unit hemodialisis, Hospital Umum Sarawak, Kuching atau di rumah anda dengan menggunakan Panduan Temubual. Tarikh temubual akan diberi mengikut keselesaan tuan/puan. Temubual tersebut akan dirakamkan.

RISIKO MENYERTAI KAJIAN

Kajian ini tidak melibatkan apa-apa prosedur dan tidak membawa apa-apa risiko.

FAEDAH MENYERTAI KAJIAN

Sekiranya anda menyertai kajian ini, anda dapat menambah pengetahuan dan kefahaman mengenai keadaan diri sendiri . Maklumat yang diberi daripada anda dapat menolong pesakit lain yang mengalami keadaan yang sama. Selain daripada itu, keputusan kajian berkemungkinan bermaafat kepada perkembangan pendidikan kesihatan yang berkesan untuk Jururawat yang memberi jagaan kepada pesakit yang menerima perawatan buah pinggang. Tambahan lagi, keputusan kajian ini dapat membantu pengesanan baru untuk penambahbaikan kurikulum pada masa depan.

MENARIK DIRI DARI KAJIAN

Sekiranya anda bertukar fikiran, anda boleh menarik diri pada bila-bila masa sahaja. Anda tidak akan mengalami apa-apa kerugian ataupun dikenakan sebarang penalti.

UNTUK MAKLUMATA LANJUT

Sekiranya anda memerlukan maklumat lanjut, anda boleh merujuk kepada saya, Lau Sie Ngo melalui siengolau@gmail.com atau di talian 016-8714338.

PENYERTAAN SECARA SUKARELA

Anda telah memahami bahawa penyertaan anda dalam kajian ini adalah secara sukarela.

MAKLUMAT SULIT

Untuk makluman anda, nama anda dan segala maklumat yang diberi adalah sulit dan tidak akan didedahkan kepada sesiapa kecuali penyelidik dan penyelia kajian ini. Segala data akan dikodkan, dianalisis dan seterusnya akan disimpan di tempat yang selamat. Maklumat peribadi akan terus dikelaskan sebagai sulit dan tidak akan dibentangkan dalam laporan kajian. Sekiranya tuan/puan setuju terlibat dalam kajia ini, sila tandatangani borang persetujuan peserta ini

Sekian dan terima kasih kerana sudi menyertai kajian ini.

Yang benar,

_____

[Lau Sie Ngo]

Nota:

1. Kajian in akan dijalankan oleh penyelidik seperti nama, dan institusi yang disebutkan di atas

2. Kajian ini telah disemak dan diluluskan oleh “Medical Research & Ethics Committee”, Kementerian Kesihatan Malaysia. Ahli jawatankuasa in bertanggunjawab kepada peyemakan dan memberi kelulusan kepada kajian yang melibatkan pesakit dan orang awam.

B: <u>BORANG PERSETUJUAN PESERTA UNTUK KAJIAN:</u>

PENGALAMAN PESAKIT KEGAGALAN BUAH PINGGANG HIDUP DENGAN HEMODIALISIS

Saya _____ (No. KP:_____) dengan sukarelanya memberi kebenaran dan mempastikan saya akan mengambil bahagian dalam kajian tersebut. Dengan menandatangani Surat Kebenaran ini, Saya mempastikan perkara-perkara berikut:

1. Saya mempastikan saya telah membaca, atau telah diterangkan dalam bahasa ibunda saya. Saya memahami maklumat mengenai kajian tersebut dan saya mempunyai peluang untuk bertanya soalan.
2. Saya memahami penyertaan dalam kajian tersebut adalah sukarela. Saya adalah bebas dan boleh menarik diri daripada kajian tersebut bila-bila masa tanpa memberi alasan. Penarikan diri dari kajian tidak akan menjejaskan jagaan dan rawatan saya.
3. Saya memahami dan bersetuju maklumat yang diperolehi dalam kajian ini mungkin diguna dalam seminar mesyuarat dan mungkin juga dibentangkan dalam majalah perubatan, tetapi maklumat saya dan lain maklumat identiti adalah sulit dan tidak akan dibentangkan. Segala maklumat peribadi akan disimpan dengan selamat dan sulit.

Peserta **Saksi**

Tandatangan;_____ Tandatangan:_____

Nama :_____ Nama :_____

NO. KP:_____ NO KP:_____

Tarikh:_____ Tarikh:_____

Deklarasi daripada penyelidik: Saya telah memberi penerangan mengenai projek kajian, dan saya percaya bahawa peserta telah memahami penerangan ini.

Penyelidik

Tandatangan:_____

Nama:_____

NO KP:_____ Tarikh:_____

Appendix J: Interview Question Guideline (English Version) ID. No:……

I am aware that these questions are personal, but your answers contribute to our better understanding of experience with end stage renal disease and life on Haemodialysis.

Section A: This section consists of questions asking for demographic data, history of illness and haemodialysis

1. Name:……2. IC No.....

3. Age:…....……. 4. Gender:……

5. Race/ethnicity:……. 6. Education level:……

7. Occupation:……8. Marital status: ……..

9. No.of children:.....

10. Year diagnosed with ESRD:…….

11. Length of time on haemodialysis treatment:.....

12. Center of Haemodialysis:……..

Section B: Questions

B.1: This section is requiring the participant to describe the experience of living with regular haemodialysis treatment and the effect of HD treatment

1. Can you please describe your experience of living with regular haemodialysis treatment?

2. How does HD treatment affect your lifestyle?

Probing questions:

a. Can you describe to me the challenges that you face?

- Physical
- Psychological
- Social
- Financial

b. How does the HD affect your activities daily living?

c. How do you feel when you undergo HD treatment?

d. What is your main worry and concern?

e. How has HD treatment affected your financial circumstances?

f. What is the problem that you face in your interaction with the other members of the society with regards to the HD treatment?

g. How does the HD affect your ability to work and your employment?

h. How has the HD affected your family (spouse, children, and others)?

i. How does the HD affect your sexual activity?

<u>B.2 : This section is requiring the participant to describe the coping mechanisms while on haemodialysis treatment</u>

1. How do you cope with the haemodialysis treatment?

Probing questions:

a. How do you manage the procedure of doing self HD treatment?

- Check blood pressure
- Body weighing

- Temperature checking
- Insertion of arteriovenous fistula needles
- Priming of the haemodialysis procedure
- Termination of HD procedure
- Haemodialysis machine

b. How do you manage your vascular or catheter access problem?

c. How do you cope with diet and fluid restriction?

d. How do you manage your medication?

e. How do you manage your daily activities?

f. How do you manage your work?

g. How do you cope with sexual difficulty?

h. How do you manage your relationship with others?

2. Is there anything else that you would like to say about life with HD treatment?

THANK YOU VERY MUCH FOR YOUR TIME AND PARTICIPATION

----------END----------

Appendix K: **Interview Questions Guideline (Malay Version)**

Lampiran K: Panduan Temubual No. ID: .....

Saya sedar bahawa soalan-soalan ini adalah peribadi, tetapi jawapan anda menyumbang kepada pemahaman yang lebih baik kepada kami mengenai pengalaman kegagalan buah pinggang peringkat akhir dan kehidupan dengan Hemodialisis.

Bahagian A: Bahagian ini terdiri daripada soalan demografi, sejarah penyakit dan sejarah hemodialisis

1. Nama: ..... 2. No. KP: ....

3. Umur: ..... 4. Jantina: .....

5. Bangsa: ..... …….6. Tahap Pendidikan: .....

7. Pekerjaan: ..... 8. Status perkahwinan: ..... .

9. Bilangan anak:…….

10. Tahun didiagnosakan mengidapi ESRD: .....

11. Tempoh menerima rawatan haemodialisis: ....

12. Pusat Hemodialisis: .....

Bahagian B: Soalan

B.1: Seksyen ini memerlukan peserta untuk menggambarkan pengalaman hidup dengan rawatan hemodialisis tetap dan kesan rawatan HD

1. Sila beritahu pengalaman anda hidup dengan rawatan hemodialisis tetap?

2. Bagaimana rawatan HD menjejaskan gaya hidup anda?

Soalan lanjutan:

a. Bolehkah anda menerangkan kepada saya cabaran yang anda hadapi?

- o Fizikal
- o Psikologikal
- o Sosial
- o Kewangan

b. Bagaimana HD menjejaskan aktiviti kehidupan anda setiap hari ?

c. Apakah perasaan anda sewaktu menjalani rawatan HD?

d. Apakah kebimbangan dan keprihatinan utama anda terhadap rawatan HD?

e. Bagaimanakah rawatan HD memberi kesan kepada status kewangan anda?

f. Apakah masalah yang anda hadapi dalam interaksi anda dengan lain-lain anggota masyarakat yang berkaitan dengan rawatan HD?

g. Bagaimana HD menjejaskan keupayaan anda untuk bekerja dan pekerjaan anda?

h. Bagaimana HD menjejaskan keluarga anda (suami atau isteri, anak-anak, dan lain-lain)?

i. Bagaimana HD menjejaskan aktiviti seksual anda?

B.2: Seksyen ini memerlukan peserta memberitahu mekanisme mengatasi masalah atau keadaan yang dihadapi sepanjang masa rawatan hemodialisis

1. Bagaimana anda boleh menyesuaikan diri dengan rawatan hemodialisis?

Soalan lanjutan:

a. Bagaimana anda mengurus prosedur menjalankan rawatan HD sendiri?

- Periksa tekanan darah
- Menyukat berat badan

- Periksa suhu badan
- Memasukan jarum ke dalam fistula arteriovena
- Priming prosedur hemodialisis
- Penamatan prosedur HD
- Mesin hemodialisis

b. Bagaimana anda mengatasi masalah vaskular akses atau kateter anda?

c. Bagaimana anda mengurus sekatan makanan dan sekatan cecair?

d. Bagaimana anda mengurus jagaan ubat-ubatan?

e. Bagaimana anda mengurus aktiviti harian anda?

f. Bagaimana anda mengurus pekerjaan anda?

g. Bagaimana anda menghadapi kesukaran seksual?

h. Bagaimana anda mengurus hubungan anda dengan orang lain?

2. Apakah yang anda ingin beritahu mengenai hidup dengan rawatan HD?

SETINGGI-TINGGI TERIMA KASIH UNTUK MASA DAN PENYERTAAN ANDA

---------- TAMAT ---------- ----------

Appendix L: Interview Questions Guideline (Mandarin Version)

附录 L：面试指南 **号码：.....**

我知道这些问题是个人的，但你的回答有助于我们对终末期肾脏病及血液透析生活的更好理解。

A 节：本节要求统计数据，疾病和血液透析的历史

1. 姓名：..... 2. 身份证号码:.....
3. 年龄：..... 4. 性别：.....
5. 种族：..... 6. 教育水平：.....
7. 职业：..... 8. 婚姻状况：.....
9. 孩子人数:……
10. ESRD 确诊年份：.....
11. 血液透析治疗时间的长短：.....
12. 血液透析中心：.....

B 节：问题

B.1 节：本节需要参与者分享常规血液透析治疗生活的经验和血液透析治疗的效果

1。请你描述您的常规血液透析治疗的经验

2。血液透析治疗如何影响你的生活方式？

其他问题：

a. 请您描述您所面临的挑战
    - 身理
    - 心灵
    - 社交
    - 财务

b. 血液透析如何影响您的日常活动？

c. 当您接血液透析治疗时，您感觉如何？

d. 什么是你的主要担忧和关注？

e. 血液透析治疗如何影响您的经济情况？

f. 血液透析治疗如何影响您的社交生活？

g. 血液透析治疗如何影响您的工作能力和就业？

h. 血液透析治疗如何影响您的家庭（配偶，子女及其他）？

i. 血液透析治疗如何影响您的性生活？

B.2 节：本节需要您形容对血液透析治疗的应对方式

1。 您如何应付血液透析治疗？

其他问题：

a. 您如何做自我血液透析治疗？

- 检查血压
- 量体重
- 体温检查
- 插静脉针
- 装置血液透析管
- 结束血液透析
- 血液透析机

b. 您如何处理您的血管或导管接入的问题？

c. 您如何应付饮食和液体的限制？

d. 您如何管理你的药物？

e. 您如何安排您的日常活动呢？

f. 您如何应付您的工作？

g. 您如何应付性生活？

h. 您如何处理您的人际关系？

2. 除此以外，您还有什么想和大家分享的？

非常感谢您的时间和参与

……

Appendix M: Interview Question Guideline (Revised version) ID. No:……

I am aware that these questions are personal, but your answers contribute to our better understanding of experience with end stage renal disease and life on Haemodialysis.

Section A: This section consists of questions asking for demographic data, history of illness and haemodialysis

1. Name:……2. IC No.....

3. Age:….....……. 4. Gender:……

5. Race/ethnicity:……. 6. Education level:……..

7. Occupation:…… 8. Marital status: ……..

9. No.of children:.....

10. Year diagnosed with ESRD:…….

11. Length of time on haemodialysis treatment:.....

12. Center of Haemodialysis:……..

Section B: Questions

B.1 : This section is requiring the participant to describe the experience of living with regular haemodialysis treatment and the effect of HD treatment

1. Can you please describe your experience of living with regular haemodialysis treatment?

2. How does HD treatment affect your life and what is the impact that you experienced?

Probing questions:

a. Can you describe to me the challenges and effect of the HD that you face?

- Physical
- Psychological
- Social
- Financial

b. How does the HD affect your activities daily living?

c. How do you feel and experienced when you undergo HD treatment?

d. What is your main worry and concern towards lifelong HD treatment?

e. How has HD treatment affected your financial circumstances?

f. What is the problem that you face in your interaction with the other members of the society with regards to the HD treatment?

- Family member
- Friend
- Dialysis staff
- Social interaction

g. How does the HD affect your ability to work and your employment?

h. How has the HD affected your family (spouse, children, and others)?

i. What is your feeling and opinion towards the following?

- Lifelong HD treatment
- HD machine
- Future

B.2 : This section is requiring the participant to describe the coping mechanisms while on haemodialysis treatment

1. How do you cope with the haemodialysis treatment?

Probing questions:

a. How do you manage the procedure of HD treatment?

- Check blood pressure
- Body weighing
- Temperature checking
- Insertion of arteriovenous fistula needles
- Priming of the haemodialysis procedure
- Termination of HD procedure

b. How do you adjusted yourself to the

- Haemodialysis machine
- HD treatment schedule which already been fixed
- Transport to and fro Haemodialysis Unit

c. How do you manage your vascular access or catheter access problem?

d. How do you cope with diet and fluid restriction?

e. How do you manage your medication?

f. How do you manage your activities daily living ?

g. How do you manage your work and employment?

h. How do you manage your relationship with spouse, family member and others

i. What is your plan and action that you have taken for your future?

2. Is there anything else that you would like to say about life with HD treatment?

THANK YOU VERY MUCH FOR YOUR TIME AND PARTICIPATION

----------END----------

Appendix N: Demographic data of participants (Name of participants are pseudonyms)

ID.	Name	Age	Gender	Race	Education Level	Length of Time on HD	Marital status	Employment	Source of Dialysis Funding
1	Aisyah	49	F	Malay	Form 5	9 years	Divorced	Yes	Government
2	Albert	39	M	Chinese	Primary 6	9 years	Married	No	Charity body
3	Brian	41	M	Chinese	Form 5	2 years 4 months	Single	No	SOCSO
4	Chik	28	M	Malay	Form 5	1 year 1 month	Single	Yes	Government
5	Daud	32	M	Malay	Form 3	10 months	Married	Yes	Government
6	Bella	48	F	Iban	Primary 2	8 months	Married	No	Government
7	Citra	59	F	Malay	No schooling	1 year 5 months	Widowed	No	Government
8	Edward	50	M	Bidayuh	Form 5	26 years	Married	Yes	Government
9	Faizu	46	M	Malay	Form 3	1 year 6 months	Married	Yes	Government
10	George	58	M	Chinese	Form 5	6 years	Married	No	SOCSO
11	Doris	53	F	Chinese	Form 3	6 years	Married	Yes	Charity body
12	Eliana	37	F	Kenyah	No schooling	12 years	Widowed	No	Charity body
13	Haron	38	M	Malay	No schooling	9 years	Married	No	SOCSO
14	Ivan	51	M	Chinese	Primary 6	7 years	Single	No	SOCSO
15	Florence	34	F	Bidayuh	Primary 6	12 years	Single	Yes	Charity body
16	Gina	43	F	Bidayauh	Form 5	16 years	Single	No	Government
17	Jaya	40	M	Jawa	Primary 2	8 years	Single	No	SOCSO
18	Kelvin	32	M	Chinese	Form 5	4 years 6 months	Single	No	SOCSO

19	Leo	57	M	Chinese	Form 5	2 years 4 months	Married	No	SOCSO
20	Mathew	51	M	Iban	Form 5	9 years	Married	Yes	Government
21	Helen	44	F	Chinese	Primary 6	13 years	Married	No	SOCSO
22	Ivy	38	F	Bidayuh	Form 6	8 years	Married	No	self
23	Nick	63	M	Chinese	No schooling	3 years	Married	No	Government
24	Oscar	61	M	Bidayuh	Form 3	1 year 7 months	Married	No	Government
25	Putra	49	M	Malay	Diploma	7 months	Married	Yes	Government
26	Quenton	59	M	Chinese	Form 5	8 years	Married	Yes	self
27	Raymond	34	M	Bidayuh	Diploma	4 years	Married	Yes	Government
28	Samuel	43	M	Chinese	Form 5	3 years 3 months	Married	No	SOCSO

Appendix O: Characteristics of the participants in number and percentage

Characteristics	Number (n)	Percentage (%)
Gender		
Male	19	67.9
Female	9	32.1
Age group		
18 to 30 years old	1	3.6
31 to 50 years	18	64.3
More than 50 years old	9	32.1
Race		
Malay	7	25.0
Chinese	11	39.3
Iban	2	7.1
Bidayuh	6	21.4
Kenyah	1	3.6
Jawa	1	3.6
Marital status		
Married	18	64.3
Single	7	25.0
Widowed	2	7.1
Divorced	1	3.6

Length of HD		
6 months to 1 year	3	10.7
1 year 1 month - 5 years	11	39.3
5 year 1 month - 10 years	9	32.1
10 year 1 month – 15 years	3	10.7
15 years 1 month – 20 years	1	3.6
More than 20 years	1	3.6
Source of dialysis funding		
Government department	13	46.43
SOCSO department	9	32.14
Charity bodies	4	14.29
Self- funded	2	7.14
Employment		
Employed	11	39.3
Unemployed	17	60.7