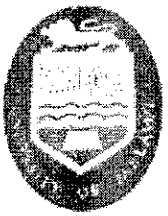

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A RESEARCH DISSERTATION SUBMITTED TO KAMUZU COLLEGE OF NURSING RESEARCH AND PUBLICATIONS COMMITTEE FOR THE AWARD OF A BACHELORS DEGREE IN NURSING

ON

PSYCHOSOCIAL EXPERIENCES OF CHRONIC DIALYSIS DEPENDENT PATIENTS AT KAMUZU CENTRAL HOSPITAL

SUBMITTED BY

DOROTHY NDEKHA MBAWA

(BSCN GENERIC YEAR 4)

SUPERVISED BY MR M. NGWALE

NOVEMBER 2010.

DECLARATION

I hereby declare that this dissertation has not been submitted for any degree and is as a result of my work not somebody else's work.

RESEARCHER : MISS DOROTHY NDEKHA MBAWA
RESEARCHER'S SIGNATURE : .....Mbawa.....
DATE : ..2ND DECEMBER, 2010.

SUPERVISOR : MR M. NGWALE
SUPERVISOR'S SIGNATURE : .....for M. Ngwale.....
DATE : ..02/12/10.....

DEDICATION

This dissertation is dedicated to my late mother Mrs. C. Mbawa. You moulded me to be the woman I am today. Wish you were here to see me take over this nursing profession form you.

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First and foremost, I would like to thank the almighty God for giving me the courage, inspiration, wisdom, the gift of life and good health to come up with the write up of this research dissertation.

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May God bless them all.

ACCRONYMS

DHO	District Health Office
IOM	Institute of Medicine
HD	Hemodialysis
ESRD	End Stage Renal Disease
KCH	Kamuzu Central Hospital
KCN	Kamuzu College of Nursing
PD	Peritoneal Dialysis
DSM-IV	Fourth edition of Diagnostic and Statistical Manual of Mental Disorder.
UNICEF	United Nations Children's Fund
USA	United States of America

DEFINITION OF TERMS

Electrolytes

Substances containing free electrically charged ions which make a substance electrically conductive.

Glomerular nephritis

The inflammation of the glomeruli of the kidney characterized by decreased production of urine and by the presence of blood and protein in the urine and by edema of body parts.

Hemodialysis

A method for removing waste products such as creatinine and urea, as well as free water from the blood when the kidneys are failing to do so.

Nephrology

The branch of medicine concerned with the physiology and diseases of the kidneys.

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ABSTRACT

This study was conducted to explore psychosocial experiences of chronic dialysis dependent patients. Its setting was KCH Dialysis unit in Lilongwe district. In order for the study to meet the expected outcomes, the study used a qualitative research design where structured in-depth interviews were conducted to collect the data from the chronic dialysis dependent patients. A sample of fifteen patients was interviewed using interview guides. The collected data was later analysed using content analysis using themes. The study has discovered that the patients experience more psychological and physical problems rather than sociological problems. It has also been discovered that the dialysis unit at KCH faces problems of frequent breakdowns of the dialysis machines, is understaffed and has inadequate dialysis machines. Basing on the data analysis, this study therefore recommends that the hospital through the Ministry of Health should consider the issue of purchasing new dialysis machines at the unit as soon as possible because the ones in use are faulty and old. The hospital management should also allocate more nurses to the unit because it is understaffed.

CHAPTER 1

1.0 INTRODUCTION

Malawi is a landlocked country located in south-east Africa. It is bordered in the north and east by Tanzania, on the east, south and south-west by Mozambique and to the west by Zambia. The health care system in Malawi is in three levels namely; the primary, secondary and tertiary levels. The country of Malawi has a population of approximately 14,841,363 million (Global Health Report, 2008) yet it only has 4 central hospitals. Almost one million people in Malawi are living with HIV and AIDS which is the leading cause of death amongst adults and Malaria is also among the most frequent reasons for outpatient visits, hospitalization and deaths in Malawi especially among under five children and pregnant mothers.

Although the government of Malawi is committed to a policy of providing primary health care to all Malawians, it is struggling to deal with other health problems for instance cardiac, renal and respiratory infections just to mention a few. Malawi experiences both cases of acute and chronic renal failure in different hospitals country wide where most of them are due to pregnancy complications, malaria, sepsis and use of herbs and chronic cases are due to hypertension, diabetes mellitus, glomerulonephritis, HIV nephropathy and other idiopathic causes (Munthali, (2010). Despite the increase of diagnosing a lot of renal failure cases countrywide, dialysis centres are not widely spread.

1.1 BACKGROUND OF THE STUDY

Renal failure is a serious medical condition affecting the kidneys where by the kidneys stop functioning properly. This dysfunction causes a build up of toxins in the body which can affect the blood, brain and heart as well as causing other complications. Once this kidney dysfunction has progressed to an extent where drugs can not reverse the situation, dialysis therapy has to be initiated.

The term dialysis refers to a process of filtering the blood, the way kidneys normally do, using a machine called dialysis machine. Dialysis machine is a machine that filters a patient's blood to remove excess water and waste products when the kidneys are damaged or dysfunctional. Several studies have claimed that early initiation of dialysis results in decrease in mortality and hospitalization rates. Dialysis does not treat renal failure, but instead keeps a person alive by performing the crucial functions of the kidneys. A person may have to

undergo dialysis as often as several times a day or 3 to 4 times a week depending on the severity of the renal failure.

Malawi just like other African countries is also facing the problem of inadequate hemodialysis services. The main concerns are high staff turnover, inadequate machines and their frequent breakdown, inadequate laboratory support, lack of drugs and supplies and patients missing their schedule due to travel issues (Munthali, 2010). Currently Malawi has one dialysis centre at Kamuzu Central Hospital in Lilongwe district which was opened in 1998 with the acquisition of four new Gambro AK200 HD machines. After three years due to lack of maintenance, all the machines had broken down and coupled with this there was a high staff turnover. In 2009 Queen Elizabeth Central Hospital (QECH) in Blantyre had one dialysis machine where 100 patients were being helped. Barely five months later since it was installed, the dialysis machine was moved to KCH forcing over 100 patients to continue travelling to the capital Lilongwe for dialysis equipment (Nyasa Times, 31st January, 2010). Currently the unit has two dialysis machines which are functioning and more than 30 patients attend dialysis sessions on appointed days of the week. Being a chronic, debilitating and terminal illness, dialysis treatment affects the daily lives of many patients and families confronted by changes in health status, lifestyles and work roles since some have to attend at least three sessions of hemodialysis in a week and the increase in the incidence of complications with tong term use of dialysis.

1.2 PROBLEM STATEMENT

Patients on hemodialysis are chronic renal failure sufferers, a devastating illness and they have to endure dialysis for life. It is recognized that psychological, sociological and even physical factors crucially influence successful rehabilitation in many patients with chronic illness. In order to improve the quality of life of these patients it will require a better understanding of their psychopathology and their views on how they wish their care can be improved. To address this need, this study is going to discuss the psychosocial experiences of the patients who attend hemodialysis sessions at Kamuzu Central Hospital.

1.3 SIGNIFICANCE OF THE STUDY

Understanding how these experiences impact on lives of dialysis dependent patients will be important to practicing nephrology nurses. Subjective representations of what living with ESRD means can support the refinement of nursing practice guidelines, formulation of

Individualized nursing care plans and priorities in evaluating outcomes of care by nurses working at the dialysis unit. The results will provide guidance to nephrology nurses about what to include as questions in nursing assessments and histories when working with this population of patients and families. Findings will also raise awareness about what it is like to live each day with this debilitating disease and dialysis.

The study findings will further help to find out if these dialysis dependent patients receive support from their significant others. It will also help the hospital to improve on the quality of care rendered to these hemodialysis patients basing on their views on the hemodialysis services after the study. Other researchers will also be assisted to identify gaps so that they can carry out more studies on dialysis in the country.

1.4 OBJECTIVES OF THE STUDY

1.4.0 BROAD OBJECTIVE

To explore psychosocial experiences of chronic dialysis dependent patients at Kamuzu Central Hospital.

1.4.1 SPECIFIC OBJECTIVES

1. To find out the psychological, sociological and physical problems that chronic dialysis dependent patients face during the course of receiving hemodialysis therapy.
2. To find out how chronic dialysis dependent patients deal with the problems they face.
3. To find out if chronic dialysis dependent patients receive support from their family and friends.
4. To find out concerns or views of chronic dialysis dependent patients on how the dialysis unit can improve on the quality of care rendered at the hemodialysis unit.

CHAPTER 2

2.0. LITERATURE REVIEW

2.1 INTRODUCTION

The initiation of hemodialysis can be stressful to some patients. These patients may experience intense and confusing emotions as they try to familiarize themselves with the lifelong therapy. End-stage renal disease (ESRD) has a significant impact upon the lives of sufferers. The experience of multiple losses especially kidney function, family role, work role, sexual function, time and mobility impact significantly on the lives of patients. Further stressors including medication effects, dietary constraints, fear of death and dependency upon treatment may affect quality of life and exacerbate feelings of a loss of control (Chilcot et al, 2008). Although this area of "psychonephrology" has been a subject of research for many years, recent work in patients with and without renal disease has advanced the understanding of the interaction of psychological, sociological and physical factors with medical outcomes.

2.2 STUDIES ON THE GLOBAL SITUATION OF HEMODIALYSIS

It has been widely claimed that depression is the most common psychopathological condition among patients with ESRD yet it is mostly under-recognized and misdiagnosed. Depressive disorder is defined by the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) as having a loss of pleasure or interest for two weeks accompanied by five or more psychological, somatic and behavioral symptoms.

2.3 PSYCHOLOGICAL PROBLEMS IN DIALYSIS DEPENDENT PATIENTS

Chilcot et al (2008), Kimmel et al (2001), AL-Homrany & Bilal (2001) and Ganzini et al (1994) in their studies showed that depression affect dialysis dependent patients with ESRD. They found that psychological and somatic effects of depression can complicate chronic illness, reduce quality of life, reduce the motivation to maintain self-care and increase hospitalization rates. Furthermore, the results from the studies showed that depression was a significant risk factor for withdrawal from HD. Ganzini et al proposed that patients with major depression should not be encouraged to make a decision about withdrawal until after a period of antidepressant treatment so that their depressive disorder should be dealt with

accordingly. Only after the antidepressant treatment, then the patient can be allowed to make a well informed decision of either withdrawing or not.

Other studies have shown that ESRD patients can display suicidal behaviors and that chronic illness can bring about feelings of guilt, loss of control, anger, sadness, confusion and fear. This has been portrayed in studies conducted by Cohen and Kimmel (2006) and Charmaz et al 2000. It was found that important risk factors include a previous history of mental illness, recent hospitalization, age of more than 75, male gender, white or Asian race, alcohol or drug dependence. It has also been discovered that these chronic dialysis dependent patients show disruptive behaviors directed mainly towards dialysis staff (Daugidas, 2007). This can be a disturbance even to other patients attending dialysis sessions at the unit. The results also revealed that financial stress can arise from the high costs of medical treatment, drugs and other health support needs such as medical supplies that are not covered by insurance or are beyond an individual's income level. This financial stress is compounded when a patient suffers a job loss, is not working during periods of treatment or lacks health insurance.

Although some studies in the world have revealed that depression is the most common symptom experienced by people under going hemodialysis treatment, Curtin et al found the opposite of these findings. In the study patients were asked to share their experiences on physical and mental dysfunction during their previous 4 weeks they had been receiving hemodialysis therapy. The results showed that a lot of patients reported lack of energy and feeling tired than mental symptoms. Furthermore, some patients reported to have experienced symptoms of dry mouth and itchy skin. A few patients reported experiences of trouble falling asleep, sexual concerns such as lack of interest in sex, inability to enjoy sex and difficulties to be sexually aroused.

2.4 FAMILY AND SOCIAL SUPPORT IN DIALYSIS DEPENDENT PATIENTS

Few studies however have addressed the association of psychosocial parameters such as family closeness and social support on how they affect dialysis dependent patients. Social support is the perception that an individual is a member of a complex network in which one can give and receive affection (Cukor, 2007). Social support in dialysis dependent patients can be received from family members, friends, pastors, acquaintances in the workplace and medical personnel and is well recognized as an important factor in the patient's adjustment to

chronic illness like renal failure. Families may be a source of social support or stress. The diagnosis of a life-threatening illness for a family member creates fear of losing the loved one and concern about the suffering he or she will endure. Family members' psychological distress can be as severe as that of the patient as such family members are sometimes considered "second-order patients" (Lederberg, 1998). Family structure and socioeconomic status are also associated with patient compliance. High levels of social support have been associated with increased utilization of medical services as Leggat *et al* (1998), Kimmel et al (2006) found out in their studies. Leggat found that patients living with someone rather than living alone were less likely to shorten HD treatments. Most of the patients who were living alone withdrew from hemodialysis treatment. It was also noted that better family coordination predicted better patient compliance with the dialysis prescription.

2.5 SOCIOECONOMIC ISSUES IN DIALYSIS DEPENDENT PATIENTS

Socioeconomic status as well as the location of the dialysis unit might also contribute to the outcome of patients with ESRD. However, not enough studies have been carried out to link lower socioeconomic status to an increased incidence of ESRD. Port *et al* in a study that was conducted in the United States of America titled "*Income and survival in chronic dialysis patients*" demonstrated that higher socioeconomic status was associated with improved survival in ESRD patients from Michigan. The results further showed that patients who were living in areas with higher socioeconomic status in the U.S had poorer outcomes but these effects were limited to minority populations. The reasons for these finding are however unclear but possibly reflect different allocation of resources among groups in the same residential area and different access to health care and services.

Although hemodialysis enables patients to survive and maintain better lives, it can sometimes cause normal lifestyles of the patients to be impaired to a large extent. Sexual dysfunction is one of the most frequently encountered health problems and should certainly be evaluated in each patient. Studies which were conducted by Arslan & Ege in 2009 and Cohen et al in 2006 revealed that chronic illness in a member of a family can radically change marital roles. In the light of these findings, it could be argued that nurses should be aware of the patient's sexual lifestyle and functioning before they are initiated on hemodialysis and later evaluate the patient's experiences during the course of receiving treatment. Sexual disturbances in the

studied patients included decreased libido, erectile dysfunction, menstrual disorders and infertility. Impotence occurred roughly in 70% of men treated with dialysis.

2.6 QUALITY OF CARE AT THE DIALYSIS UNIT

The dialysis unit and staff might play an important role in determining outcomes, but few studies have addressed this issue. McClellan and colleagues in their study which was conducted in 1991 showed that dialysis unit staff exhibit specific characteristics over time despite a high turnover rate of dialysis dependent patients. In the study dialysis dependent patients were interviewed about their level of satisfaction with their nurses, technicians and nephrologists at the unit. Most patients showed increased satisfaction with physicians but not with nursing or technical personnel. However the study did not specify the reasons.

A number of studies have shown that physicians substantially underestimate chronically ill patients' psychosocial distress (Fallowfield et al, 2001; Keller et al, 2004). Inattention to psychosocial problems has also been reported by chronically ill patients suffering from different types of cancers, heart failures and renal failure survivors in focus groups (IOM, 2007). The IOM report revealed that the vast majority of problems in the quality of health care are not the result of poorly motivated, uncaring or unintelligent health care personnel but instead result from numerous barriers to high-quality health care in the systems that prepare clinicians for their work and structure their work practices. Some of these barriers occur at the level of the patient's interaction with the clinician (e.g., poor communication between the patient and his/her health care providers).

The psychosocial problems described above can adversely affect health and health care in many ways. For example, a substantial literature has documented low income as a strong risk factor for disability, illness, and death in chronic dialysis patient (Subramanian et al., 2002). Inadequate income limits people with chronic illnesses the ability to purchase food, medications and health care supplies necessary for health and health care as well as to secure necessary transportation and obtain relief from other stressors that can accompany tasks of everyday life. As noted above, lack of transportation to medical appointments and other out-of-home health resources is common and it can pose a barrier to health monitoring, illness management and health promotion.

2.7 STUDIES OF THE HEMODIALYSIS SITUATION IN AFRICA

Renal disease especially glomerular disease is more prevalent in Africa and seems to be of a more severe form than that found in Western countries. However, the availability of dialysis is quite variable in Africa. Services are still predominantly urban and therefore generally inaccessible to the poorer and less educated rural patients (Naicker S, 2003).

2.8 PROBLEMS FACED BY DIALYSIS DEPENDENT PATIENTS

In view of this problem, Fogazzi et al (2001) and Bamgboye E.L (2003) conducted studies in West African countries of Benin, Togo and Nigeria with the aim of finding out the difficulties which these West African countries encounter with hemodialysis. The results revealed that lack of major basic diagnostic and therapeutic facilities such as electrolyte measurement, urine culture, renal biopsy and lack of money for those patients who were not affording to pay for the dialysis services were the main problems which resulted in the mismanagement of dialysis dependent patients. The results further showed that dialysis dependent patients could not attend hemodialysis sessions due to lack of government funding, subsidy and health insurance to cover the relatively high costs of hemodialysis. In addition to the problem of lack of funding, it was also discovered that the majority of patients lived far away from existing dialysis centers such that they were travelling long distances to get dialysis treatment. The study findings also indicated that many of the dialysis machines were outdated and were frequently breaking down. Other problems which were encountered included frequent public power supply disruptions and erratic water supply. Brain drain was also found to be a major problem. Many kidney specialists, dialysis nurses and even technicians were emigrating to the Middle East and to the Western countries so that they could enjoy better standards of living. Some of the staff working in public hospitals engaged in private practice at the expense of public service such that the quality of care at the public hospitals suffered. Furthermore, nationwide strikes among doctors, nurses and support staff were disrupting dialysis operations. During these strikes, many of the patients did not afford to switch to the privately run dialysis units. As a consequence, many of them died by the time the units eventually reopened.

Lent and his colleagues also conducted a retrospective study from January 1987 to June 1991 at Groote Schuur Hospital (GSH) in Cape Town, South Africa to evaluate the socioeconomic statuses of dialysis dependent patients who attend sessions at the clinic. The results showed that their psychosocial profiles were mainly average to poor. By contrast, whites were mainly of higher social class, their psychosocial profile was average to good. As such Blacks faced a lot of complications like infections to due to non compliance than the whites and also because of low social economic status. During the time the study was being conducted a lot of blacks had problems to access the hospital and attend the dialysis sessions due to their low social economic status. This study therefore suggested that poor socioeconomic condition is a problem in the utilization of dialysis.

To identify issues related to renal replacement therapy in ESRD patients in the developing world, a study was conducted in Nigeria at Jos University Teaching Hospital in June and July 2003 by Agaba and his colleagues. They analysed the practice and costs of hemodialysis in Nigerian ESRD patients. where ten ESRD patients were dialysed. It was found that the cost of dialysis was borne by the patients and their families and it revealed that the great majority of Nigerians could not afford three times weekly dialysis sessions. Under dialysis in Nigerian ESRD patients is common and caused by socioeconomic factors and technologic deficits. One step towards correction of under dialysis could be sharing of the cost of dialysis by the public.

2.9 STUDIES OF HEMODIALYSIS IN MALAWI

Despite a number of people being treated with hemodialysis in Malawi, no studies have so far been done in Malawi to find out the views of chronic dialysis dependent patients regarding their prescribed long term therapy.

2.10 CONCLUSION

The literature review has shown that ESRD sufferers especially in those that have been initiated on dialysis is stressful, both to the patient and his or her significant others. Studies have revealed that many patients experience changes in sexual dysfunction, some experience depression and others fail to follow dialysis prescriptions due to lack of funds to pay for the hemodialysis services and even money for transportation to and from the dialysis unit to mention a few. This study is therefore important as it aims at exploring the psychosocial experiences of chronic dialysis dependent patients in Malawi.

CHAPTER 3

3.0 SUBJECTS AND METHODS

3.1 STUDY DESIGN

This study used a qualitative research design. Polit and Beck (2006) define a qualitative study design as an investigation of phenomena typically in an in-depth and holistic fashion through the collection of rich narrative materials. This design was used because the study depended on the interaction with the participants in order to get detailed information. The interaction allowed me to understand the situation more so that I can begin to make sense of the data collected and properly analyze the data. Structured individual in-depth interviews were conducted to collect the data from the patients. I believed that to investigate on personal experiences it would greatly require the patients to give self reports than to put all the patients under study in one group and conduct focus group discussions.

3.2. STUDY SETTING

The study took place at Kamuzu Central Hospital in Lilongwe. This site was chosen because it was the only place in Malawi where this hemodialysis therapy was being offered before the opening of dialysis units at Mwaiwathu Private Hospital and Queen Elizabeth Central Hospital in August and October respectively. The interviews were conducted at the hospital after seeking consent from the hospital director and the matron of the dialysis unit.

3.3 SAMPLING

A sample of ten patients was interviewed not fifteen patients as it was earlier planned in the proposal. It was deliberate because some of the client had transferred to Queen Elizabeth Central Hospital and Mwaiwathu Private Hospital where they had opened dialysis units. The subjects in this study were those patients who had chronic renal failure and were attending a couple of hemodialysis sessions in a week. The participants were only those patients who had been on this treatment for more than a month. This criterion of recruiting subjects to take part was considered because I felt these people can be in a good position to share tentative experiences on their long-term treatment therapy. In addition, those who had been on the therapy for more than a month would at least have had some experiences on how the sessions were positively or negatively affecting their lives. A total of seven male patients and three female patients were interviewed. A greater number of male participants were realised

because most of the patients who attend the services at the clinic were males than females. The reason for this male preponderance was however unclear. Different sources of literature have also indicated that a lot of males are usually initiated on hemodialysis than females. Data from Kamuzu Central Hospital Dialysis Unit had revealed that more men attend dialysis sessions than females.

3.4 PILOT STUDY

The pilot study was conducted at the same unit because then Kamuzu Central Hospital was the only centre where dialysis was being offered. Two participants were interviewed to pretest the interview guide.

3.5 DATA COLLECTION

Interview guides were used as tools for collecting data. The tool was designed in English and was also translated in Chichewa because many people in Malawi speak Chichewa and for easy communication. The interview guide contained open ended questions to allow the subjects to explain in full their experiences. The researcher asked the matron of the unit to single out a room where the interviews were being conducted. The interviews were being conducted before, during or after the hemodialysis session according to the patient's preference. This was so because some patients felt relaxed after they had been on the hemodialysis machine while others could take part before or when they were being dialysed. Each interview was taking approximately 1 hour. The data was collected during the patient's follow up visits at the dialysis unit. The data was collected for two weeks.

3.6 DATA ANALYSIS

After all data collection, the researcher analyzed the collected data. Content analysis using themes was used to analyze the collected data. The process of data analysis involved reading each transcript thoroughly, identifying the information provided, developing the codes, applying the codes developed into the content and comparing the transcripts to identify what was similar and different about the reasons given.

3.7 ETHICAL CONSIDERATIONS

Ethical considerations are important especially in research dealing with human beings because they provide the basis for moral conduct in respect of human dignity and integrity. To ensure that subjects have ethical protection, subjects participated in this study voluntarily

and gave an informed consent. Before participating in the study, each participant was given an explanation about the nature and purpose of the study and they had the right to take part or not. After the participant had understood the nature of the study, he or she was requested to sign a consent form which would serve as evidence that the participant had agreed to participate in the study without being forced.

Confidentiality of information from the subjects was respected and the accessibility of data was restricted to the researcher and her supervisor. The participants were assured that in no way would the researcher disclose information in the manner traceable to any of the subjects. Confidentiality was also considered because it is an important ethical requirement in research of which failing to comply can owe the researcher various implications. Some people may not want the information they have provided to be linked with them. To further ensure strict confidentially of the information obtained, all interview tools were destroyed at the end of the study. Each participant was interviewed separately in a room where the participant was with the researcher alone.

Anonymity of the participants was also ensured such that code numbers were used instead of real names. Furthermore, ethical approval and study clearance was obtained from KCN research and publications committee. Letters requesting permission to conduct the study at the study setting were written to Kamuzu Central Hospital. The study had no ethical implications because it posed no physical or psychological harm to the participants.

3.8 DISSERMINATION OF RESULTS

The findings of this study have been disseminated through a written report and copies have been sent to KCN library and KCH Dialysis unit.

CHAPTER 4

4.0 PRESENTATION OF FINDINGS

4.1 INTRODUCTION

The findings of this study are a reflection of the in depth interviews conducted amongst the 10 subjects which were interviewed at Kamuzu Central Hospital's dialysis unit. This is the presentation of the study findings on the psychosocial experiences of chronic dialysis dependent patients. The findings focus on psychosocial, sociological and physical problems that dialysis dependent patients face, how chronic dialysis dependent patients deal with the problems faced, the support the chronic dialysis dependent patients receive from their significant others and how the dialysis unit can improve on the quality of care rendered at the unit.

4.2 GENERAL QUESTIONS

The participants in this study were all chronic dialysis dependent patients who had been on dialysis treatment for more than a month prior to the interview. Their period on dialysis fell between four months to four years.

When the participants were asked if anyone in their family ever suffered from kidney disease nine participants denied having heard of or having a member of family who had ever suffered from kidney disease and was initiated on dialysis except for one participant who reported that his uncle suffered from kidney failure. When the participant was probed to explain more he said;

> *"I was 55 years old when my uncle suffered from acute kidney failure. I believe hypertension precipitated his condition. Unfortunately he died before he was dialysed although it was prescribed".*

Upon asking the participants if they know the underlying cause of their kidney disease, three quarter of the participants responded that they know. Only a quarter reported that they are not aware of what caused their kidney disease. When probed further on the underlying diseases that caused their initiation on dialysis a great number of the participants mentioned diabetes,

followed by hypertension and two participants mentioned benign prostate hypertrophy and alcohol poisoning.

When the participants were asked for how long they had been on the treatment their responses ranged from four months to five years. It was also found that half of the subjects attended the dialysis sessions twice in a week while the remaining half were attending the dialysis sessions thrice in a week. When asked if the participants had experienced improvements ever since they were initiated on the dialysis, the majority of the participants reported to have been experiencing improvements and a few denied having experiencing improvements. Among the participants who said they were experiencing improvements they reported the following quotations;

"I can walk alone, I can drive and I no longer vomit than I used to do at first".

"I have an increased appetite, no headaches and my body feels lighter after being dialysed".

"I used to experience diarrheal episodes during the early days of my initiation on dialysi.s but now this stopped".

A few revealed that they experience no improvements;

"I do not feel good at all and I have lost weight".

"I see no change. I keep on vomiting, my legs keep on swelling and I feel exhausted everytime I am dialysed".

4.3 PSYCHOSOCIAL, SOCIOLOGICAL AND PHYSICAL PROBLEMS THAT DIALYSIS DEPENDENT PATIENTS FACE.

Among some of the issues that the researcher wanted to find out from the participants were the participants' psychosocial, sociological and physical problems that the dialysis dependent patients face during the course of receiving dialysis treatment.

The interviews revealed that all the participants had been experiencing problems ever since they were initiated on dialysis. When probed further to explain their problems it was

discovered that most of them experienced psychological, physiological and physical problems than sociological problems. Three of the participants reported that that they experience the problems of anaemia often, headaches, body aches and sometimes shiver when they are being dialysed.

"I usually fail to meet my doctors for review on my appointed days. I get so worried".

"I experience terrible headaches after being dialysed. My doctors assured me that this was going to stop but it is three years now and I see no change".

"Usually I am found with low haemoglobin levels and sometimes I am not dialysed because the nurses and doctors fear that I may collapse during dialysis".

Two reported that they are sexually weak ever since they started dialysis treatment. One of the participants was quoted saying;

"My friend down there does not work at all, he does not erect".

The rest reported having psychological problems which included worries about their life and future of their children.

Although the majority of the patients reported that they have no problems with transportation since they use personal cars, a few participants complained that they find problems with transport to ferry them to and from the hospital on their appointed days of dialysis. One of the participants said;

"I rely on an ambulance from Kabudula Health centre everytime to bring me here. When the ambulance is not coming here (KCH) on my appointed day, I stay home. And sometimes it happen that am here at the hospital but the ambulance has failed to get me back home. In such a situation I sleep in the ward".

The participants were further asked if they experience problems with their marital life and it was revealed that half of the participants encounter marital problems while the other half denied having any marital problems. One of the participants who reported that he experiences marital problems was quoted saying;

> *"My wife does not feel satisfied everytime we make love because I fell to erect. I see it in her eyes and for that reason she is promiscuous".*

Another participant said;

> *"I feel weak everytime I have the urge to sleep with my wife. I cannot perform. My energy is all gone with this therapy".*

Although half of the participants reported to have marital problems, some responded that their spouses understand them, others said their sexual energy was not affected by the dialysis sessions while others had lost their spouses and failed to comment on this.

> *"Whenever I am not feeling well my husband understands me".*
>
> *"Personally I have never experienced any marital problems with my wife. She is still with me and we have a baby girl who was born earlier this year. We do no quarrel at all".*

When the participants were asked whether they were employed or were working for any company or organization, many were found to be retired civil servants and rely on their children for support, a few reported that they run their own businesses and only one participant was employed though he had stopped working for three months then because of his condition.

The participants were also asked about the effects of the problems they encounter on their long term therapy. The responses that were realised showed that the majority of the participants had been experiencing psychological torture because of the problems they face. The participants reported the following;

"I spend sleepless nights thinking where I would get transport money to use when going to the hospital on my appointed dates".

"I cannot walk by myself. I depend on someone else's support to walk. I know that I am a burden to my wife since she always has to support me when I am walking".

"I will die soon. I have no future anymore. My children will suffer. When am not dialysed my whole body feels heavy because a lot of toxic substances accumulate in my blood".

While other participants reported that the problems they encounter have an effect on their long term therapy, a few reported that they experience no problems.

4.4 HOW CHRONIC DIALYSIS DEPENDENT PATIENTS DEAL WITH THE PROBLEMS FACED.

In this study the researcher also wanted to find out if the chronic dialysis patients have solutions to the problems they face. In response to this half of the participants reported to have the solutions while the rest said they do nothing about the problems. All of them reported that no one assists them to solve the problems. To probe further on the solutions they have the following was reported;

"Whenever I am shivering I lit a heater to keep myself warm. The nurses also give me ferrous tablets whenever my hemoglobin levels are low".

"I call the doctor in advance to make up the appointment date and time. If it happens that he will not be around on that day, he refers me to his colleagues".

"I just put everything in God's hand to intervene because my human wisdom fails me to solve the problems".

Participants who reported that they find problems with transportation were asked on how they deal with the problems of transportation. The following responses were given out;

> *"When I run short of transport money I try my best to go round and borrow from friends. But sometimes it happens that they too do not have the money".*
>
> *"I rented a house here in Lilongwe that is where I live during the weekdays. During the weekends I visit my family in Blantyre".*

One of the participants who said he has no solutions to the problems he encounters reported the following;

> *"I have no solutions to the problems I face. When the ambulance is not available at the nearby health centre which takes me to the hospital, I miss the dialysis sessions. I can not afford to board a bus to the hospital. I usually do not have money I depend on my relatives who sponsor me".*

Those participants who reported that they experience marital problems explained that they just touch their wives private parts and kiss them until they satisfy their sexual desires.
When the participants were asked whether they find time to attend the dialysis sessions on their appointed days, all responded that they find time, they have no engagements which prevent them from attending the sessions.

4.5 SUPPORT FROM FAMILY AND FRIENDS

The aim of this study was also to assess if the dialysis dependent patients receive support from their family and friends. When they were asked almost all the participants responded that they are supported by their family relations especially parents, children, uncles and

cousins except for one participant who said she has nobody who supports her. A few reported that they do receive support from friends.

> *"I have two children who are abroad. One is in the United Kingdom and the other in South Africa. They send me money every month to pay rent, feed and hire a taxi to and from the hospital".*
> *"My brother is the one who gives me transport money to travel from Mchinji to the hospital."*
> *"I can not bathe and walk on my own. My wife assists me with bathing and walking".*

Another participant said;

> *"My husband who was my family here in Malawi died in the early 1990s. All my children are in India and they do not care. I am alone here".*

When the participants were asked on the type of support they receive many reported that they get financial support, spiritual and moral support and others assist them with activities of living like bathing and toileting. Most of them also reported that sometimes they receive air tickets from their children inviting them to see specialists abroad. For the majority who responded that they receive support from their significant they revealed that the support is sufficient.

4.6 HOW THE DIALYSIS UNIT CAN IMPROVE ON THE QUALITY OF CARE

When the participants were asked how they interact with health workers at the unit all the participants were so glad with the care that the nurses render to them. They reported that the nurses are very hard working, they greet them with a smile, they give the patients food whenever food is available and they are dedicated because they work even during odd hours especially when some machines have developed faults. One said;

> *"When I compare the attitudes of nurses in South Africa and these two nurses at this unit they are <u>VERY</u> different. The nurses here have never uttered bad words towards*

me or my fellow patients. They are so kind and caring I only find problems with doctors who most of the times are not available at this unit. ".

To further assess if the participants feel satisfied with the care they receive at the unit, they were asked to report whether they feel satisfied with the care given or they feel unsatisfied. Three quarters of the participants reported that they felt satisfied with the care because they do not pay to get the services and for the Malawian standards the unit is good. Quarter of the participants said they feel unsatisfied with the care that is rendered at this unit. One participant explained that;

"I believe when one is getting treatment he or she has to be cured and go home no more visits to the hospital. But I wonder why I keep on coming here for treatment. I wish I had a kidney transplant but this hospital cannot do a kidney transplant".

When they were asked to describe the care they receive in their own words a few participants described it as *"very good"* while the rest ranked it as *"good"*. When they were asked whether they experience problems with the unit, all responded that they had problems. The problems that were highlighted included no entertainment at the unit, failure and frequent breakdown of dialysis machines, the unit being small, inadequate staff (two nurses only), unable to meet physicians for review and like spirit and dialysate not available most of the times. The participants further responded that they feel these problems can be solved by the management of the hospital. The participants were asked to share their views and suggestions on how the problems they encounter can be solved to improve dialysis services at the hospital. The majority of the participants wished if the hospital management could write a proposal to the ministry of health requesting new dialysis machines. A good number of the participants suggested that the hospital should increase the number of nurses working at the unit because two nurses are not enough. Socially some participants suggested that the unit should have a radio or a television set to keep them entertained when they are being dialysed.

Some participants thought that the best way was to repair all faulty dialysis machines as soon as possible since procuring new equipment maybe a long process.

CHAPTER 5

5.0 DISCUSSION OF THE FINDINGS

5.1 INTRODUCTION

This chapter aims at discussing the key issues arising from the study findings. The discussion of the findings mainly focus on the psychosocial, sociological and physical problems that dialysis dependent patients face, how chronic dialysis dependent patients deal with the problems faced, the support the chronic dialysis dependent patients receive from their friends and relatives and how the dialysis unit can improve on the quality of care rendered at the unit. Recommendations and conclusion are made for future considerations.

5.2 GENERAL QUESTIONS

The results of this study have revealed that most of the participants did not have the history of kidney disease in their family. However, the study has revealed that most participants experienced kidney failure because of their underlying diabetes and hypertension diseases although other few participants presented with different underlying causes of alcohol poisoning and benign prostate hypertrophy. In Malawi cases of diabetes and hypertension are very common both at outpatient and inpatient departments. People in the country have little knowledge that these two diseases can bring about kidney failure if they are left untreated. Hypertension can cause damage to the blood vessels and filters in the kidney making removal of waste products from the body difficult (www. dialysis-patient-care.blogspot.com). Early diagnosis of these underlying causes of kidney disease can help to halt the progression of kidney disease to kidney failure. The findings of this study are inline with what Fogazzi et al (2001) found in the countries of Benin and Togo where they wanted to establish a nephrological program. The results of the study revealed that common causes of chronic renal failure leading to dialysis were hypertension, indigenous remedies, glomerulonephritis, diabetes mellitus and malformations. Alebiosu et al in (2006) also found that the commonest causes of chronic renal disease among the patients were chronic glomerulonephritis with 41.2%, hypertensive nephrosclerosis 26.1% and diabetes mellitus 13.1%. It was also noted

that most of the patients who attend dialysis sessions have been on this treatment for some time. As such they had the experience to respond well to the questions of this study. It was found that almost all the participants have access to dialysis treatment although the attendance varies in days. The attendance on different days may suggest that the machines are not enough for the patients to be dialysed on the same days and also because of their frequent break downs. As such, there is a need for the hospital to take action to procure new dialysis machines. Majority of the participants also reported that they experience improvements after they have been dialysed. This is an evidence that dialysis really removes toxic substances in the bodies of those patients whose kidneys have failed.

5.3 PSYCHOSOCIAL, SOCIOLOGICAL AND PHYSICAL PROBLEMS THAT DIALYSIS DEPENDENT PATIENTS FACE.

The participants were asked if they face problems either psychologically, sociologically or physically considering the fact that dialysis is a life long therapy.

The interviews revealed that most of the participants experience psychological and physical problems rather than sociological problems. The problems included marital problems, transportation and body changes for example body aches, anaemia and shivering. It is essential that chronic renal sufferers who are on hemodialysis therapy in Malawi should know about these effects of long term use of dialysis. It is the role of the nurses who provide direct nursing care and the doctors at the unit to explain about some of the side effects that these hemodialysis patients may experience with long term use of dialysis to prepare the patients' mind psychologically. The findings from this study are being supported by Curtin et al (2002). In their study where patients were asked to share their experiences on their physical and mental dysfunction, the patients reported experiences of trouble falling asleep, sexual concerns such as lack of interest in sex, inability to enjoy sex and difficulties to be sexually aroused. The same has been discovered in my study. When the participants were asked if they experience marital problems some participants responded that they do. Some said they feel sexually weak everytime they have the urge to make love and they also fell to erect. This is also similar to a study that was done in Turkey on the sexual experiences of women exposed to hemodialysis. The findings revealed that of the ten women who were interviewed seven of them reported that they had been experiencing sexual problems. Through these study

findings, it has shown that sexual dysfunction is one of the most frequently encountered health problems and should certainly be evaluated in each patient. In the light of these findings, it could be argued that nurses should be aware of the patient's sexual lifestyle before commencement of hemodialysis therapy so that the resulting effects should be immediately evaluated when rendering individualized care.

Subramanian et al (2002) pointed out that inadequate income limits people with chronic illnesses the ability to purchase food, medications and health care supplies necessary for health and health care as well as to secure necessary transportation to the hospital. The same was reported by the participants of this study where some participants reported that they fail to attend dialysis sessions on their appointed days because they have no means of transport or transport money to take them to and from the hospital. This is also supported by Bamgboye (2003) who is his study discovered that most dialysis patients live far away from existing dialysis centers, so that they have to travel long distances to receive dialysis treatment. Consequently, dialysis is frequently inadequate. As noted above, lack of transportation to medical appointments can pose a barrier to health monitoring, illness management and health promotion. With the current Malawian situation on hemodialysis where these services are urbanized, it is therefore important for nurses at the KCH dialysis unit not to generalize that the patients do not find problems with transportation. Although the majority of the participants have personal cars, there are some patients who find problems with transportation because they live far away for example in districts outside Lilongwe. Nurses in Malawi especially nephrology nurses should always remember the fact that people are biopsychosocial beings with different needs. As such nurses should consider dialysing those patients who rely on an ambulance or public transport to ferry them to and from the hospital first so that they could be catching the ambulance or the bus in time. This can also be supported by the nursing ethical principle of justice (distributive justice) which mainly focuses on fair and equitable distribution of scarce resources in a hospital setting.

However, from the study the findings have also revealed that the problems chronic dialysis dependent patients face have negative effects on the patient's care. The patients experience psychological problems because they feel they are a burden to their families since they have to be assisted with activities of daily living for example, bathing and toileting and some fail

to source money for transportation to and from the hospital as such the toxic substances just accumulate in their bodies. This leads to high rates of admissions in the medical wards at the hospital. There are close links between emotional well being and clinical outcomes in dialysis patients. Life style modification is important for stress handling in dialysis patients. This may also suggest that hemodialysis therapy should be incorporated in palliative care in this Malawian setting. This can be argued that hemodialysis involves the type of care which focuses on alleviating the problem without dealing with its cause to promote maximum functioning of the body. This is what palliative care in Malawi is all about.

It was also noted that most of the participants were not working as they used to prior to the commencement of the dialysis treatment. Majority of the participants reported that they experience a lot of physiological problems after being dialysed such as weakness, shivering and abdominal pains just to mention a few. These prevent them from working actively in their various work places resulting into premature resignation. As such most of the participants opted to establish their own businesses rather than working where as others solely depend on their family and friends for assistance.

5.4 HOW CHRONIC DIALYSIS DEPENDENT PATIENTS DEAL WITH THE PROBLEMS FACED.

From the findings, it has been noted that some of the chronic dialysis dependent patients manage to solve the problems they encounter during the course of receiving dialysis treatment although others fail to solve them. Unresolved problems of patients frequently result in patient's abscondment from the hospital in our Malawian setting as such this often leads to treatment failure and consequently treatment non complice. Sometimes because patients have unresolved problems, they may miss their appointed days to the hospital which hinder them to access hemodialysis care. The saddest part of this is premature deaths of patients. To effectively solve the problems these dialysis dependent patients face, social support from the hospital and family members needs to be available. Cukor (2007) describes social support as the perception that an individual is a member of a complex network in which one can give and receive affection.

5.5 SUPPORT FROM FAMILY AND FRIENDS

It was very interesting to realize that the findings of the study revealed that the majority of the participants receive support from their family and friends except for one participant. Most of them reported that they are supported financially, spiritually and even morally. They further reported that the support is sufficient because they are able to meet their daily needs. When the patients are being supported by either their families or friends, they have a sense of belonging. Family and friends also play role treatment compliance and the support they render to patients assist in allaying anxiety. As Leggat *et al* (1998) and Kimmel et al (2006) pointed out in their studies, high levels of social support have been associated with increased utilization of dialysis services by those patients dependent on dialysis. If the dialysis dependent patients are supported by their significant others, the burden of the problems they face will be solved hence maximizing the patients' response to dialysis therapy.

5.6 HOW THE DIALYSIS UNIT CAN IMPROVE ON THE QUALITY OF CARE

When the participants were asked how they interact with health workers at the unit all the participants were so glad and pleased with the care that the nurses render to them. They described the behavior of the service providers especially nurses as very hard working, they greet them with a smile, they give them food whenever food is available and they are dedicated. Other participants reported that the nurses work even during odd hours especially when some machines have developed faults. Although the nurses were praised by the majority of the participants, other participants raised concerns that the doctors are not available most of the times at the unit. This makes their medical reviews difficult because there is often no one to review them. This is opposing to what McClellan et al (1991) found in their study. Most patients who were interviewed in their study showed increased satisfaction with physicians but not with nursing or technical personnel. However the study did not specify the reasons. The dedication of the nursing personnel is very important when rendering nursing care to patients. By virtue nurses pledge in their pledge of service that the total health of the patients will be their first consideration. With this in mind, it can be said that the nurses at KCH dialysis unit are morally right and are meeting the nursing profession standards.

Despite realizing the above mentioned responses, a lot of participants at KCH dialysis unit ranked the care they receive at the dialysis unit as "good". This suggests that the nurses are able to meet the medical needs of the patients despite the fact that doctors are not available most of the times at the unit.

Another area of interest was to find out the problems that chronic dialysis dependent patients meet at the dialysis unit. Most participants reported a problem of frequent breakdown of the dialysis machines, inadequacy of the dialysis machines and the unit being understaffed. For the continuity of hemodialysis care, the dialysis machines have to be in good working conditions all the time. Malawi being a developing country relies solely on donations to run the health sector. To be precise, for the country to purchase new dialysis machines it will require well wishers to donate to the ministry of health. The country also has problems with technical personnel who are responsible for the repairing of the dialysis equipment when it is faulty. Current situation at KCH dialysis unit waits for trained personnel from South Africa who is knowledgeable in repairing the dialysis machines. This disturbs the delivery of care at the dialysis unit. As highlighted in his study, Bamgboye (2003) found that Nigeria experiences the same problems. The study revealed that many of the dialysis machines in Nigeria are outdated as a result they frequently breakdown.

The reason of understaffing at the KCH dialysis unit was found to be lack of funds to train more nephrology nurses and doctors. This is in contrast with what Bamgboye (2003) found in Nigeria. The study indicated that many Nigerian kidney specialists and dialysis nurses emigrate to the Middle East and the Western world so that they can enjoy a better standard of living. Furthermore it discovered that nationwide strikes among doctors and nurses disrupted dialysis operations. Therefore, the hospital management of KCH should make an initiative to write a proposal to the donor community as soon as possible so that the new dialysis machines should be procured before the old machines are completely out of use.

The research also sought individual suggestions and views on how the problems faced by the participants at the unit can be rectified so that quality of care can be improved at the unit.

The assessment established that the majority of the participants thought that the hospital management could play a major role in solving the problems faced. A good number of the participants suggested that the hospital should write a proposal to the ministry requesting new

machines and it was also suggested by most participants that the hospital should recruit and train more nephrology nurses and doctors because two nurses are not enough. Socially a few participants suggested that the unit should have a radio or a television set to keep them entertained when they are being dialysed. Most participants thought that the best way was to repair all faulty dialysis machines as soon as possible since procuring new equipment maybe a long process. These suggestions so far indicate that the chronic dialysis dependent patients feel that the hospital management is in a good position to intervene on the problems faced by the dialysis unit.

5.7 CONCLUSION

All in all, this research has sought answers to the objectives that the researcher set aside prior to the study in order to explore psychosocial experiences of chronic dialysis dependent patients at Kamuzu Central Hospital.

The subjective views of the participants have revealed that the chronic dialysis dependent patients face a lot of psychological and physical problems rather than sociological problems, the majority of the patients are able to deal with the problems they face during the course of receiving hemodialysis treatment, they receive support from their family and friends and have highlighted that in order for the dialysis unit to improve on the quality of care rendered at the unit, the hospital management is in a good position to intervene on the problems faced by the dialysis unit.

5.8. RECOMMENDATIONS OF THE STUDY

- The government of Malawi has to consider purchasing some more dialysis machines to be planted in all regions of the country. Therefore, the hospital management of KCH through the ministry of health should make an initiative to write a proposal to the donor community as soon as possible so that the new dialysis machines should be procured before the old machines are completely out of use. It can be of great help also if the dialysis therapy can be extended to all district hospitals country wide.

- Introduction of new dialysis centres will also mean that a lot of nurses and doctors have to be trained in the field. This will also assist patients who travel long distances to attend dialysis sessions at KCH.

- Following the results that have been realised in this study, the researcher had the opinion that subjective representations of experiences that chronic dialysis dependent have reported can support the refinement of nursing practice guidelines, formulation of individualized nursing care plans and priorities in evaluating outcomes of care by nurses working at the dialysis unit.

5.9. IMPLICATIONS OF THE STUDY

5.9.0 NURSING PRACTICE

- Being a long term therapy, chronic dialysis dependent patients need a lot of psychological support rather than physical support of being dialysed at the unit. It has been recognized that psychological and sociological factors crucially influence successful rehabilitation in many patients with chronic illness. Published experiences of chronic dialysis dependent patients in different parts of the world have suggested that psychological factors are among critical variables in determining good response to treatment. This therefore implies that practicing nephrology nurses at the unit should provide comprehensive care to the patients which should include all aspects of human life for example, physical, spiritual, social and psychological care.

5.9.1 NURSING MANAGEMENT

- Nurse managers (the chief matron) at the hospital should ensure fair and equitable distribution of nursing staff in all departments, the dialysis unit inclusive.
- Supervision by Matrons at the unit should be done to evaluate care given to the dialysis patients to find out if it is according to the nursing standards.

5.9.2 NURSING EDUCATION

- The nursing curricula in all nursing training institution should be reviewed. More hours should be added to medical surgical nursing course so that the topics of kidney failure and dialysis therapy should be fully covered during theory. This will assist nurse graduates to at least have basic knowledge on kidney failure and dialysis in addition to the nephrology orientation training that is given before they become practicing nephrology nurses.

5.9.3 NURSING RESEARCH

- In Malawi there are no research studies that have been conducted and precisely concerning dialysis. Since nursing is a profession that provides holistic care to anyone regardless of the person's social standing, race, nationality, religion or political background, nurses should take the responsibility to conduct research studies in this area.
- Incorporating the findings of the research studies in nursing research will also help to improve the care rendered to the chronic dialysis dependent patients.

5.10 AREAS FOR FURTHER STUDY

A lot more studies on dialysis have to be conducted in Malawi. The following areas have been suggested;

- The same study of psychosocial experiences of dialysis patients but with a large sample to establish non biased results that will represent the experiences of the dialysis dependent patients on a wider note.
- How to improve the quality of dialysis services in Malawi.

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APPENDICES

APPENDIX 1: INTERVIEW GUIDE (ENGLISH VERSION)

AN INTERVIEW GUIDE ON PSYCHOSOCIAL EXPERIENCES OF CHRONIC DIALYSIS DEPENDENT PATIENTS

Participant code number: ..... **Date of interview: .....**

Time interview started: ..... **Ended: .....**

Total time for the interview: 1 hour.

SECTION A: ICE BREAKER (10 MINUTES)
You are welcome to take part in the interview.

1. Did anyone ever suffered from kidney disease in your family before?
2. If yes, how is/was the person related to you?
3. When did the person started suffering from kidney failure?
4. Then, how old were you?
5. Did you establish the cause of his or her kidney disease?
6. If yes, what was it?
7. Was the person initiated on dialysis?
8. Do you know the underlying cause of your kidney disease?
9. If yes, what is it?
10. For how long have you been on this hemodialysis treatment?
11. How many times a week do you attend the dialysis sessions?
12. Are you experiencing any improvements ever since you started this hemodialysis therapy? Explain.

SECTION B: PSYCHOLOGICAL, SOCIOLOGICAL AND PHYSICAL PROBLEMS THAT DIALYSIS DEPENDENT PATIENTS FACE (15 MINUTES)

13. With the fact that you attend a couple of hemodialysis sessions per week, do you face problems either psychologically, sociologically or physically ever since you were initiated on this treatment?

If yes probes,

- *Mention the problems you encounter?*

14. How do you travel to and from your home to the clinic with the fact that you attend a couple of dialysis sessions per week?

15. What happens when you have no means of transport to take you to the dialysis clinic?

16. Do you experience problems with your marital life ever since you were initiated on this hemodialysis treatment?

If yes probes,

- *What are they? Mention the problems.*

17. Are you employed by any company or organisation?

If yes probes,

- *Do you find time to access hemodialysis treatment on the appointed days?*
- *What challenges do you face at your work place? Mention them.*

18. What effects do the problems you encounter have on your long-term treatment therapy?

SECTION C: HOW CHRONIC DIALYSIS DEPENDENT PATIENTS DEAL WITH THE PROBLEMS FACED (15 MINUTES)

19. Do you have solutions to solve the problems you face during the course of receiving hemodialysis treatment?

Probes

- *What are the solutions?*
- *Do you manage to solve them on your own?*
- *If not, who assists you?*

20. How do you solve the problem of transportation?

21. Explain how you deal with the marital problems you mentioned in question 16?

22. Explain how you balance your time to attend hemodialysis sessions on your appointed days with your work?

23. Explain how you solve the challenges you meet at your work place that hinder you to access hemodialysis sessions on the appointed days?

SECTION D: SUPPORT FROM SIGNIFICANT OTHERS (10 MINUTES)

24. Do you receive support from your family, friends or other people during this course of receiving dialysis treatment?

If yes probes,

- *Who give you the support?*
- *What kind of support do they provide?*

25. Is the support you get sufficient?

Probes,

- *If it is sufficient, explain why you feel it is sufficient.*
- *If it is not sufficient, why do you feel it is not sufficient?*

SECTION E: HOW THE DIALYSIS UNIT CAN IMPROVE ON THE QUALITY OF CARE (10 MINUTES)

26. How do you interact with the health workers at this unit?

27. Do you feel satisfied with the care that you receive at this dialysis unit?

Probes,

- *If you feel the care is satisfactory, explain why you think so?*
- *If you feel the care is unsatisfactory, explain why you think so?*
- *How can u describe the care that is provided at this dialysis unit in your own words?*

28. Do you find problems with the care that is rendered at this dialysis unit?

If yes, probes,

- *What are the problems?*

29. Do you think these problems can be solved?

If yes probes,

- *What are your views or suggestions on how the problems can be solved to improve dialysis services at this hospital?*

Thank you very much for your participation in the study.

APPENDIX 2: INTERVIEW GUIDE-CHICHEWA VERSION

KAFUKUFUKU WOFUNA KUDZIWA ZOMWE ANTHU OMWE AMAKHALA PA MAKINA OTHANDIZIRA IMPSYO AMAKUMANA NAZO KUYAMBIRA NTHAWI YOMWE ANAYAMBA KULANDIRA CHITHANDIZOCHI MPAKA PANO.

Nambala..... **Tsiku.....**

Nthawi yoyambira..... **Nthawi yomalizira.....**

Nthawi yonse.....

GAWO LOYAMBA: MAFUNSO OYAMBIRA (MPHINDI ZINAYI)

Muli olandiridwa kutengapo gawo mukafukufuku ameneyu.

1. Alipo wina m'banja mwanu amene anadwalapo matenda okhudza impsyo?
2. Ngati wina anadwalapo, anali ndani wanu?
3. Anayamba liti kudwala matendawo?
4. Pa nthawi imene ankadwalayo, inuyo munali ndi zaka zingati?
5. Munkadziwa chimene chinayambitsa matenda a abale anuwo?
6. Ngati mukuchidziwa, chinali chiyani?
7. Anayamba kulandira chithandizo kupyolera mumakina othandizira impsyo?
8. Nanga inuyo mumadziwa mumadziwa chimene chinayambitsa matenda anuwa?
9. Ngati mumachidziwa ndi chani?
10. Kodi mwakhala nthawi yaitali bwanji kuyambira pamene munayamba kudwala matendawa?
11. Kodi mumakhala kangati pa makina amenewa pa sabata?
12. Mukuona kusintha kulikonse chiyambileni kukhala pa makina othandizira impsyowa?Fotokozani.

GAWO LACHIWIRI: ZOVUTA ZOMWE ANTHU AMENE AMAKHALA PA MAKINA OTHANDIZIRA IMPSYO AMAKUMANA NAZO (MPHINDI ZISANU).

13. Kutengera kuti mumayenera kudzalandira chithandizo chokhala pa makina othandizira impsyowa kangapo pa sabata, pali mavuto amene mumakumana nawo chiyambileni?

Ngati inde,

- *Tchulani mavuto amene mumakumana nawo?*

14. Kodi mumayenda bwanji kuchokera kunyumba kwanu pobwera kuno ku chipatala?

15. Zimatha bwanji mukasowa mayendedwe opitira kuchipatala?
16. Pali mavuto amene mumakumana nawo okhudza moyo wa m'banja?

Ngati inde,

- *Ndimavuto anji? Tchulani.*

17. Kodi mumagwira ntchito?

Ngati inde,

- *Mumapeza nthawi kuti mudzalandile thandizoli?*
- *Pali mavuto anji amene mumakumana nawo omwe amakulepheletsani kubwera kuchipatala kuno?*

18. Kodi mavuto amene mumakumana nawowa amakhudza bwanji chithandizo chomwe mumalandira?

GAWO LACHITATU: ZOMWE ANTHU OMWE AMAKHALA PA MAKINA OTHANDIZIRA IMPSYO AMACHITA POTHANA NDI MAVUTO AMENE AMAKUMANA NAWO(MPHINDI ZISANU).

19. Pali njira zomwe mumatsata kuti muthane ndimavuto amene mumakumana nawowa?

Ngati inde,

- *Ndinjira zanji?*
- *Mumathana nawo mavutowa panokha?*
- *Ngati mumalephera, amakuthandizirani ndi ndani?*

20. Tafotokozaniko m'mene mumathanirana ndi mavuto omwe mwatchula pa funso 13?
21. Kodi nanga vuto lamayendedwe mumathana nalo bwanji?
22. Nanga mavuto am'banja omwe mwatchula pa funso 16 aja mumathana nawo bwanji?
23. Nanga mumakwanitsa bwanji kugawa nthawi yanu yobwera kuchipatala kuno ndi nthawi ya ntchito?
24. Nanga mavuto amene mumakumana nawo kumalo komwe mumagwira ntchito mumathana nawo bwanji?

GAWO LACHINAYI: CHITHANDIZO KUCHOKERA KWA ABALE (MPINDI ZISANU)

25. Kodi mumalandira chithandizo kuchokera kwa abale ndi alongo kuyambira pomwe munayamba kukhala pa makina othandizira impsyowa?

Ngati inde,

- *Tchulani amene amakuthandizaniwo(ubale wake ndiwotani)?*
- *Ndithandizo lanji limene amapereka?*

26. Kodi thandizoli limakukwanirani?

- Ngati thandizoli limakukwanirani, ndi chifukwa chani mukuganiza kuti ndilokwanira?
- Ngati thandizoli silimakukwanirani, ndi chifukwa chain mukuganiza kuti ndilosakwanira?

GAWO LACHISANU: ZIMENE CHIPATALA CHA IMPSYOCHI CHINGACHITE KUTI CHIZIPELEKA CHITHANDIZO MOYENERA(MPHINDI ZISANU NDI IMODZI).

27. Kodi ubale wanu ndi anthu ogwira ntchito kuchipatala chino cha impsyo ndiwotani? Fotokozani?
28. Mumakhala okhutitsidwa ndi chithandizo chimene chimapelekedwa kuno ku chipatala cha impsyo?

- *Ngati inde, ndi chifukwa chani mumakhutitsidwa ndi chithandizo chimene chimaperekedwa kuno?*
- *Ngati ayi, ndichifukwa chani simumakhutitsidwa ndi chithandizo chomwe chimapelekedwa kuno?*
- *Mu mawu anu, mungafotokoze bwanji za chithandizo chomwe chipatala chino chimapeleka?*

29. Pali mavuto ena ali onse amene mumakumana nawo okhudzana ndi kapelekedwe ka chithandizoku chipatala chino?

- *Ngati inde, tchulani*?

30. Mukuganiza kuti mavuto amenewa akhoza kukonzeka?

Ngati inde,

- *Muli ndi mfundo kapena maganizo anji pa momwe mukuonera kuti mavutowa angakonzedwere kuti chipatalachi chizipeleka chithandizo choyenerera?*

Zikomo kwambiri potenga nawo mbali mukafukufuku ameneyu.

APPENDIX 3: CONSENT FORM (ENGLISH VERSION)

University of Malawi

Kamuzu College of Nursing.

Dear Participant,

I am Dorothy Mbawa, a student from Kamuzu College of Nursing one of the constituent college of the University of Malawi. I am in the final year of study. In partial fulfillment of the programme i am required to conduct a research study to be awarded a degree in nursing. As such i write to request for your consent to participate in this study.

The study topic is psychosocial experiences of chronic dialysis dependent patients at Kamuzu Central Hospital. The study findings will help the hospital to improve on the quality of care given to dialysis dependent patients.

To participate in this research study, you must have been on this treatment for more than a month because you can be in a good position to share tentative experiences on this long-term treatment therapy.

Data will be collected through structured in-depth interviews using an interview guide. No names will be used instead code numbers will be used to provide anonymity. The information obtained will be kept confidential such that interview tools will be destroyed at the end of the study. The interviews will be taking twenty-five minutes and will be conducted at the dialysis unit. Participation in this study is voluntary. You will be free to withdraw from the study at any time even after you have already accepted or started taking part in the study without being penalized in any way. No financial or material assistances will be offered for your participation in the study.

The research activities will not have any harm on your health and you are also free to ask questions about the study. After you have understood the nature of the study I will request you to sign a consent form below which will serve as evidence that you have agreed to participate in this study without being forced.

Dear Researcher,

I, the undersigned have fully understood the study and its procedures. I am willing to take part in the study and I hereby give an informed consent to participate in the study.

Signature of Participant..... **Date**.....

Signature of Researcher..... **Date**.....

APPENDIX 4: CONSENT FORM (CHICHEWA VERSION)

University of Malawi

Kamuzu College of Nursing

Okondedwa Bambo/mayi,

Dzina langa ndi Dorothy Mbawa mmodzi mwa ophunzira ku sukulu yaunamwino ya Kamuzu koleji yomwe ndi gawo limodzi la sukulu ya ukachenjede ya dziko la Malawi ndipo ndili m'chaka chomaliza. Malingana ndi maphunziro amenewa, ndili oyenera kupanga kafukufuku wondiyenereza kuti ndidzalandire digiri yanga. Kotero ndikufuna kupempha chilolezo chanu kuti mutengeko mbali mukafukufuku ameneyu.

Kafukufuku amene ndikupangayu ndikufuna kudziwa zimene anthu amene amadzalandira chithandizo kupyolela mumakina othandizira ipsyo amakumana nazo kuyambira nthawi imene anayamba kulandira thandizoli pa chipatala cha Kamuzu Central. Pali chiyembekezo choti zotsatira za kafukufuku ameneyu zizathandiza kuunikira chipatala cha Kamuzu Central mmene angapelekele chithandizo chapamwamba kwa odwala matenda okhudza ipsyowa.

Kuti mutenge mbali mukafukufuku ameneyu mukuyenera kukhala kuti mwakhala mukulandira thandizoli koposera mwezi umodzi chifukwa ndikukhulupilira kuti mutha kufotokoza bwino lomwe zomwe mwakhala mukukumana nazo kuyambira pomwe munayamba kulandira chithandizochi.

Mukafukufuku ameneyu chipepala chamafunso chidzidzangwiritsira ntchito pocheza nanu. Inu mukavomera kutenga mbali zomwe mudzatiuze zidzakhala zachinsinsi ndipo zinthu zonse zimene ndizagwiritse ntchito pakafukufuku ameneyu ndidzaziotcha pamapeto pa kafukufukuyu ndi cholinga choti anthu ena asadzaone zomwe inu munanena. Kucheza kumeneku kuzidzakhala mpindi makumi awiri ndi zisanu ndipo tizidzakambirana kuchipatala cha ipsyo komweko. Kutenga nawo mbali mukafukufuku ameneyu sikokakamiza. Muli ndi ufulu wosankha kutenga nawo mbali mu kafukufuku ameneyu kapena ayi. Muli ololedwa kusiya mutavomera kale kutenga mbali opanda chilango chilichonse. Mukudziwitsidwanso kuti mukatenga mbali mukafukufuku ameneyu simudzapatsidwa thandizo lililonse la ndalama.

Ine ndamvetsetsa zomwe kafukufukuyu akufuna ndipo ndili osangalatsidwa kutenga nawo mbali kotero ndikupeleka chilolezo changa.

Dzina la ofunsidwa mafunso ..... Date.....

Dzina la ofunsa mafunso..... Date.....

APPENDIX 5: CLEARANCE LETTER TO KCN RESEARCH COMMITTEE REQUESTING TO CONDUCT A STUDY AT KCH

University of Malawi
Kamuzu College of Nursing
P/Bag 1
Lilongwe.

The Research Committee
University of Malawi
Kamuzu College of Nursing
P/Bag 1
Lilongwe.

Dear Sir/Madam,

RE: APPLICATION FOR PERMISSION TO CONDUCT A STUDY AT KAMUZU CENTRAL HOSPITAL

I am a student at Kamuzu College of Nursing doing my final year of studying a Bachelor of Science Degree in Nursing. In partial fulfillment of this programme, I am required to conduct a research study as such I am writing to request for your approval to conduct a research study at Kamuzu Central Hospital.

The study is aimed at exploring the psychosocial experiences of chronic dialysis dependent patients. The results of the study will help the hospital to improve on the quality of care rendered to the dialysis dependent patients. It will also help other researchers to identify gaps so that they can carry out more studies on dialysis in the country. Participants will either be male or female clients attending dialysis sessions at the hospital.

I am therefore looking for your favorable response or approval

Yours Faithfully,

MISS DOROTHY MBAWA

APPENDIX 6: A CLEARANCE LETTER TO THE HOSPITAL DIRECTOR REQUESTING TO CONDUCT THE STUDY AT KCH

University of Malawi
Kamuzu College of Nursing
P/Bag 1
Lilongwe.

The DHO
Lilongwe DHO
P.O. Box
Lilongwe.

Dear Sir/Madam,

APPLICATION FOR PERMISSION TO CONDUCT A STUDY AT KAMUZU CENTRAL HOSPITAL

I am a student at Kamuzu College of Nursing doing my final year of studying a Bachelor of Science Degree in Nursing. In partial fulfillment of the Bachelor of Science programme, I am required to conduct a research study.

I am writing to request for your permission to conduct a research study at your institution. The study is aimed at exploring the psychosocial experiences of chronic dialysis dependent patients. The results of the study will help the hospital to improve on the quality of care rendered to the dialysis dependent patients. It will also help other researchers to identify gaps so that they can carry out more studies on dialysis in the country.

Your acceptance will be greatly appreciated.

Yours Faithfully,

DOROTHY MBAWA

APPENDIX 7: APPROVAL LETTER FROM KCN RESEARCH AND PUBLICATIONS COMMITTEE

APPENDIX 7: APPROVAL LETTER FROM KCN RESEARCH AND PUBLICATIONS COMMITTEE

University of Malawi
KAMUZU COLLEGE OF NURSING

RESEARCH AND PUBLICATIONS COMMITTEE

APPROVAL CERTIFICATE

TITLE: **Psychosocial Experiences of Chronic Dialysis Dependent Patients at Kamuzu Central Hospital**

INVESTIGATOR: **DOROTHY DNEKHA MBAWA**

DEPARTMENT/YEAR OF STUDY:

REVIEW DATE : SEPTEMBER 2010

DECISION OF THE COMMITTEE: Approved

UNIVERSITY OF MALAWI KAMUZU COLLEGE 04-10-2010

SIGNATURE: ..... **DATE:** 04-10-10

CHAIRPERSON, RESEARCH AND PULBICATIONS COMMITTEE

cc Supervisor:

DECLARATION OF INVESTIGATOR(S)

I/we fully understand the conditions under which I am/we are authorized to carry out the above mentioned research and I/we guarantee to ensure compliance with these conditions. In case of any departure from the research procedure as approved, I/we will resubmit the proposal to the committee.

DATE 09/10/10 SIGNATURE(S) Mbawa