



INSTITUTE OF HEALTH
FACULTY OF HEALTH SCIENCES
SCHOOL OF NURSING

LIVED EXPERIENCE OF CHRONIC RENAL DISEASE PATIENTS WHO ARE ON
HEMO DIALYSIS: PHENOMENOLOGICAL STUDY AT JIMMA UNIVERCITY
MEDICAL CENTER, SOUTH WEST ETHIOPIA, 2022

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Abstract

BACKGROUND: *Chronic kidney disease is a common non-communicable disease that is becoming a worldwide health problem. Chronic kidney disease is a gradual and permanent loss of kidney function. Hemodialysis is one of the managements for chronic kidney disease. Even though dialysis replaces the healthy kidney, it has limitations and adds an additional burden to the individual's life, but here is a limited study in Ethiopia especially in Jimma that shows the lived experience of chronic kidney disease patients with hemodialysis.*

OBJECTIVE: *To explore lived experiences of chronic kidney disease patients receiving hemodialysis in Jimma University Medical Center, Jimma city, south west Ethiopia, 2022*

METHODOLOGY: *A qualitative approach, phenomenological study design was carried out to explore the experience of purposively selected eight chronic kidney patients who are on hemodialysis. In-depth interviews were conducted using local language Amharic by using interview guide. The interviews were transcribed and translated in to English, and the data were analyzed using qualitative data management software (Atlas ti version 7.1.4). Thematic analysis was done.*

Results: *This study explored five major theme (1) the perception and biological aspect of CKD (2) Challenges faced by chronic kidney disease patients (3) Emotional disturbance and consequence of CKD (4) diverse outlook towards the machine and care at dialysis unit and (5) coping mechanism with the level of their illness and the challenge they face.*

Conclusions: *Financial constraint is the main challenge faced by chronic kidney disease patients which deteriorates their life, challenge to obtain the service and they are obliged to live with the support of others. Due to the nature (seriousness) of the disease the patients hindered from actively involved in social activities and previous work; as a result the patients think the disease is serious and trying to kill themselves. Ministry of Health and regional health bureau and other stakeholders should give attention on the means of supporting or decreasing the costs of dialysis and medications up to making it for free through health insurance coverage.*

KEY WORDS: *Chronic renal disease, hemodialysis, lived experience*

Acronym

CKD: - Chronic Kidney Disease

ESRD: - End stage renal disease

GFR: - Glomerular filtration rate

HD: - Hemodialysis

HRQOL: - Health related quality of life

JUIRB: -Jimma university institute of review board

JUMC: - Jimma university medical center

Km: - Kilo meter

PI: - Principal investigators

US: - United state

WSU-TRH: - Wolaita Sodo University teaching and referral hospital

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Table of Contents

Abstract.....	iii
Acronym	iv
Acknowledgements.....	v
List of Tables	vii
CHAPTER ONE.....	1
Introduction.....	1
1.1. Background	1
1.2. Statement of the problem	3
1.3. Significant of the study	5
CHAPTER TWO	6
LITERATURE REVIEW	6
CHAPTER THREE	9
OBJECTIVE	9
3.1. General objective of the study.....	9
3.2. Specific objectives of the study	9
CHAPTER FOUR.....	10
METHOD AND MATERIALS	10
4.1. Study setting and period.....	10
4.2. Study design.....	10
4.3 Study Participants.....	11
4.3 Participants Recruitment.....	11
4.4. Data Collection procedure.....	11
4.5. Trustworthiness.....	12
4.7. Data analysis.....	13
4.8. Operational Definitions	13
4.9. Ethical consideration	13
4.10. Dissemination plan.....	14
CHAPTER FIVE	15
RESULT	15
CHAPTER SIX.....	30
Discussion	30
Strength and limitations	33
CHAPTER SEVEN: Conclusion and recommendation.....	34
Reference	36
ANNEX-I-ENGLISH VERSION DATA COLLECTION TOOL	42
II. Interview Guide English version.....	45
ANNEX-III - In-depth Interview Guide Amharic Version.....	46

List of Tables

Table 1 <i>Description of participant characteristics in JUMC HD center southwest Ethiopia, 2022</i>	15
Table 2 <i>Major themes and categories of the study finding conducted at JUMC HD center, 2022</i>	16

CHAPTER ONE

Introduction

1.1. Background

Chronic kidney disease (CKD) occurs when there is a longer than three-month persistence of abnormal kidney composition or function (1). Higher creatinine levels and a decreased glomerular filtration rate serve as indicators (2).

Based on the level of glomerular filtration rate, CKD is divided into five phases (3). There may not be any symptoms in the early stages, but they steadily grow worse. Chronic kidney disease's terminal stage is an irreversible, severely disabling condition of the kidneys that demands for dialysis or kidney transplantation as rigorous treatments(2). Increased risks of cardiovascular disease, early mortality, and/or worse quality of life are associated with CKD at any stage (4).

By definition, CKD is a progressive, permanent impairment in the renal task, which results in metabolic, fluid, and electrolyte imbalances in the body(3). Each day, healthy kidneys filter around 200 quarts of blood; they also excrete extra fluid, salt, and waste items through urine. When this function is lost for an extended period of time, it causes harm to lives(5). The best overall indicator of renal function is generally acknowledged to be GFR. We define reduced GFR as a GFR <60 ml/min/1.73 m², and renal failure as a GFR <15 ml/min/1.73 m² (6).

End-stage renal disease (ESRD) can be treated in one of three ways: transplantation, peritoneal dialysis (PD), or hemodialysis (HD). The Centers for Medicaid and Medicare (CMS) prefer kidney transplantation over the other two because it improves quality of life (QOL) and more closely replicates the normal functions of the kidneys (7).

Hemodialysis is still the most widely used form of therapy in the world (8),utilized by at least 80% of patients in over 70% of reporting countries (9). A vein drained of blood during hemodialysis. To get rid of the trash, filters are used. After that, the blood is returned to the body. Typically, hemodialysis is carried out in a dialysis facility. Three times a week, in three to four-hour sessions (10).

Although hemodialysis extends life, the complicated nature of the treatment process impacts patients' daily lives and increases their symptom burden (11,12). Among the most common symptoms are sleep disorders, peripheral neuropathy, infection, fatigue, stress, anxiety, and depression, cognitive changes, pain, and sexual dysfunction (13,14). Additionally, As a result

of grafts or fistulas for dialysis access, it also affects patients' perceptions of their bodies, and the high cost of dialysis therapy causes a severe financial crisis. Therefore, independence and relationships were in danger (15).

ESRD becomes financial burden on family and health care sector due to a high morbidity and mortality associated with it(16). The accessibility of renal replacement therapy (RRT) is scarce in the Ethiopian context and only the affluent can afford to maintain their treatment regimen. Therefore, many patients' life is at risk because of lack of dialysis to the majority of the population(17).

1.2. Statement of the problem

Globally, more than 500 million people are affected by CKD(1,18). The incidence of CKD has continued to rise at a rate of 8% per year and consumes up to 2% of the overall global health expenditure(19).

This costly disease affects men more often than women and African Americans more than any other ethnic group. The literature has long documented that ESRD affects African Americans at a higher rate than other races(20).

In low and middle-income countries including Ethiopia, due to the shift of lifestyle and urbanization, and the increased prevalence and incidence of diabetes mellitus and hypertension the burden of CKD is alarmingly increasing(21,22). The prevalence of CKD in Ethiopia is high and has increased in the last few years to be 12.2% which shows it is becoming one of the public health problems(23).

A cross sectional study done in Jimma university medical center among adult greater than 18 year old total 208 study participants about awareness, prevalence and risk factors of chronic kidney disease among diabetes mellitus and hypertensive patient prevalence of CKD was 26% (24). Annually, in Ethiopia, deaths related to renal disease exceeded 12,000 people (1.47% of total deaths)(25).

More than one million people in the world with severe CKD are being treated with some form of therapy, with 90% of these patients living in developed countries(4). Hemodialysis (HD) has been proved to be the most common treatment modality in End-Stage Kidney Disease (ESKD) and more than three million patients all around the world are undergoing HD annually(26,27).

In the Sub-Saharan Africa region including Ethiopia, even though many patients with CKD initiate HD treatment, because of an inability to pay for ongoing dialysis; up to 85% of the patients are forced to withdraw from the HD treatment(28). In Ethiopia, Each CKD patient's expenses for each hemodialysis treatment are more than 1000 Ethiopian Birr (30 US\$)(17). Currently, in Ethiopia, there are few dialysis centers found in public hospitals(29). Three in Addis Ababa (Zewditu Memorial, Saint Paulo's Millennium Medical College, and Tikur Anbessa) hospitals and two in northern Ethiopia (Bahir Dar Felege Hiwot, and University of Gondar comprehensive specialized) hospital and Wolaita Sodo University teaching and referral hospital (WSU-TRH) HD centers giving service(30).

Patients on dialysis face psychological, social, economic, sexual, and medical problems(31–33). According to the study conducted by Cohen, Cukor, and Kimmel demonstrates that anxiety is a common psychological problem in the CKD population. They emphasized that anxiety as a problem is a frequently overlooked psychiatric symptom in patients with ESRD treated with hemodialysis (HD)(34).

Another research on lived experiences of CKD patients in Queen Zewditu Memorial Hospital identified points such as diagnosis with the disease, denial, social declining, work problems and economic challenges in relation to paying for dialysis regimen, covering for medication and transportation were the major challenges for this particular population. Overall, this research plays important role in illuminating the problem CKD population face from their own perspectives(35).

The treatment requires sticking to the dietary restrictions, medications, renal Replacement therapy (RRT) and biochemical balance; otherwise, (31)result in positive health outcome are impossible for patients. In a reciprocal manner, this medical expectation results in psychosocial challenges. However, there is scarce research in investigating the life encounters of ESRD patients in the Ethiopian context(36).

There are a number of quantitative studies assessed hemodialysis patients' quality of life, coping and adaptation(37–39), However studies conducted to understand the lived experiences of chronic renal disease patient who are on hemodialysis is very little. Though, the data indicated the problem and HD user confirms that is growing from time to time, calls the attention of researchers to carry out an in depth inquiry to further realize the experience of the patients. Examining individuals' experiences during HD is important to exploring and gaining insights into the experiences and perspectives of individuals about diverse phenomena. It also provides set certain reliable information on the possible means of way forwards.

Thus the main purpose of the research is to explore the lived experience of chronic renal disease patient who are on hemodialysis in Jimma university medical center, Oromia Ethiopia.

1.3. Significant of the study

The primary importance of this research is to increase knowledge in understanding the meaning CKD patients attach to chronic kidney disease and the treatment modalities and will help for interdisciplinary teams of health professionals, and researchers, to see the extent of the problem, design solutions for encountered problems and to improve services. In addition to that primary role of nurse is to deliver care for the client in relation to this study for the CKD patient who is on hemodialysis. For that reason relevant for them to understand how jimma medical center hemodialysis unit client with CKD live their lives. It will be input for raise quality of care and to provide information that will be valuable to improving the effectiveness of holistic care. Also used as a base line for future studies to investigate in this area.

CHAPTER TWO

LITERATURE REVIEW

A qualitative research conducted in Addis Abeba revealed that patients who received hemodialysis experience biological aspects of CKD among the various biological features of CKD, living with multiple conditions, fatigue and bodily symptoms are mentioned. The study participants explained that they are living with two or more chronic conditions. The interview results indicate that most participants besides ESRD condition, struggle with diabetes, hypertension, cardiac diseases, anemia, bone and mineral disorder, lung disease and gastrointestinal complications(40). The patients also expressed that they have different symptoms such as headaches, nausea, and vomiting while and after dialysis treatment. Moreover, the participants disclosed that fluid overload and skipping treatment sometimes results in edema in their extremities (40).

The study conducted in Bahirdar on lived experience of CKD patient with hemodialysis reported that patient experiences seriousness of the disease. As of the respondents Conditions that make it too difficult to live with the disease were the poor outcome, lifelong treatment, restriction in full participation in their social life and daily activity, and expenses associated with the treatment(41).

End stage renal disease requires a continuous treatment plan that urges the patient to take costly hemodialysis three times a week. A study carried out in Nigerian patients compares the disease with a death sentence. The research shows that in Nigerian society it is beyond the capacities of the patients to maintain hemodialysis treatment. Therefore, only those who afford it can continue their treatment while many die at an early stage(42) Another studies in Felege-hiwot comprehensive specialized hospital illuminates the hard reality in the economic hurdles of this group. The study shows that patients struggle to pay for hemodialysis, medication and transport fees. This research also concludes that patients found the economic aspect of treatment very difficult to manage(41).

Due to the chronicity of the disease and the nature of treatment process the CKD patient who are on HD are hindered from actively involved in social activities. This shows that they are restricted in participating in social events as a result of the treatment procedure they undergo(43). Other research also mentioned that those patients who use in service

hemodialysis might reduce patient interaction in their social life and they can't visit their family and friend outside of the clinic setting(44)

The same study indicates that life while undergoing hemodialysis is an experience of abundant losses. Participants explained that they lost their physical strength because of the disease. The loss experienced made them to narrate that, life is filled with change and can never be compared to the life lived before(44).

Researches indicate that maintaining job is difficult for patients on hemodialysis. The progression of the disease and the nature of treatment impacts patients to make changes in relation to their employment. The study shows that dialysis changes the lives of patients at different levels. Employment is one of the numerous difficulties encountered by individuals with progressive CKD transitioning to ESRD. These patients face multiple disincentives to employment, including medical, logistical, and financial disincentives(45).

The study conducted on lived experiences of patients undergoing hemodialysis with the concept of care implied that because of frequent dialysis sessions, and also insufficient ability to work hard and continuously as before the participant not able to work as before, because of this they lost their job (46).

As of the study conducted on lived experience of patients undergoing hemodialysis: the participants expressed a deep grief over the inability to take water and food as per to the heart's desire and felt it really disgusting. Thus the compelling force to adhere to fluid and diet restrictions was another aspect which made the participants to perceive their lived experience as hard pressed(47).

A study conducted in Felegehiwot specialized hospital on the lived experienced patient on hemodialysis reported that how CKD has placed limitations on their lives. Even though participants feel as they live a limited life, they strictly adhere to fluid and diet restrictions(41).

As the studies shows that patients who are on hemodialysis conveyed as unable to preserve their spiritual and ethnic customs resulting from, lack of energy, fatigue, leg cramps. Fatigue was one of side effects that happed after dialysis management and persistent to the next day which results unable to complete responsibilities and sustain occupation, produce feelings of depression, doesn't have good relation with their partners or significant others(44).

Studies that investigated the direct experience of ESRD patients show that HD patients have lower health status and display more physical and psychological symptoms such as anxiety, sleep disorder and suicidal thoughts(48). On the other hand, studies indicated that patients who suffer from psychological trouble experienced various losses that induced depression(49).

The dialysis machine was perceived by the CKD patient in different way, some of them believed as the machine was an important instrument for supporting the life of the patient and the patient can't sustain without it (37, 39).

Health care provider played an important role in patients' abilities to handle the problem related to hemodialysis. Sustaining good communication and providing enough information about the procedures also have significant positive aspects for patients, in addition empathy for their circumstances have significant role(50).

According to the study conducted on existential and religious dimensions of spirituality and their relationship with health-related quality of life in chronic kidney disease found out religion as an important element that contributes to the patients' survival. He stated in his finding that religion provides hope and increases social support for the patients(51). Faith in God and prayers for healing, talking and sharing the patient's condition and the challenges to their friends, relatives, healthcare workers, colleagues, and talking to self were the participants coping mechanisms identified in this study(52).

The research indicated that patients with higher social support scores had improved survival rates. According to the study conducted on hemodialysis patients confirmed that a higher level of support at the start of dialysis is associated with low risks of hospitalization as well as greater satisfaction of life and HRQOL in the beginning year(53).

Emotional support of the family was another extracted concept and participants stated that emotional support of family members is an integral part of care: 'I'd like my wife and my children to listen to me and spend more time with me; when they are with me, I'm not afraid of the disease(46).

CHAPTER THREE

OBJECTIVE

3.1. General objective of the study

- To explore lived experiences of chronic renal disease patients receiving hemodialysis in Jimma medical center, Jimma, south west Ethiopia 2022

3.2. Specific objectives of the study

- To explore the perspectives of chronic renal failure patients on their underlying medical condition
- To explore the effect of chronic renal failure on patients' social and relational issues
- To explore the psychological experiences of participants that emerged from the disease condition
- To explore the coping strategies of chronic renal failure patients

CHAPTER FOUR

METHOD AND MATERIALS

4.1. Study setting and period

The study was conducted at Jimma university medical center (JUMC), an area located in Jimma town, Oromia region South west Ethiopia, 356 km away from Addis Ababa. JUMC is a teaching and the only referral hospital for the south west region. It is estimated that 20 million catchment populations get services. The hospital has 800 beds and about 500 clients visit the hospital daily. Jimma university medical center started giving hemodialysis service as public service in 2011, whether it is chronic renal failure or not. According to the information obtained from the hospital (2021 report), the hospital provided a hemodialysis service for over 12 CKD patients by two hemodialysis machine. These patients got 2 times hemodialysis service in a week and it costs about 3000 birr during the starting of hemodialysis and then 700 Ethiopian birr for one session.

The study was conducted from July 1 to 30 2022.

4.2. Study design

A qualitative approach, descriptive Phenomenological study design was carried out to explore the lived experience of chronic renal disease patients who were on hemodialysis at JUMC.

Phenomenological study design approach was chosen, because Phenomenology is concerned with the study of experience from the perspective of the individual. To be able to fully describe the experience of chronic renal disease patients who were on hemodialysis, the researcher entered deeply into the experience. This is possible using phenomenological approach using in-depth interview. The purpose of phenomenological research is to describe phenomena as they are lived and experienced by individuals.

Phenomenological approaches are more effective in describing rather than explaining subjective realities, the insights, beliefs, motivation and actions and folk wisdom by clearly showing the research participants.

4.3 Study Participants

According to Creswell 1998, the only legitimate informants in the phenomenological study participants are those who passed through the experience related to the targeted thematic issue of the study(54). In this study, the study participants were CKD patients who are on hemodialysis in Jimma university medical center.

4.3 Participants Recruitment

The recruitment of participants was employed by using criterion (purposive) sampling, to obtain deep information on lived experiences of CKD patients on HD, participants were selected from different age groups, marital status, distance from the hemodialysis center, duration of hemodialysis and capability of paying for the service.

Eight CKD patients who were on hemodialysis were interviewed, as it was the recommended sample size for research of this kind; for phenomenological research by interview, Creswell (1998) recommends 5-25 participants(55). Information saturation was used to indicate for the termination of further inclusion of participants. The data were being collected until no new or relevant information has been attained.

Participants were identified from the hemodialysis (HD) center patient registration number and their schedule of HD procedure with the aid of HD center coordinator.

Participants' addresses, the duration of care, and the date of appointment for the next HD was obtained from the patients' registration book. The CKD patients who are on hemodialysis and who met the eligibility criteria were contacted by phone through the Dialysis center coordinator. Those who have the willingness to participate in the study had given a chance to choose the place that could be comfortable for them for the interview.

4.4. Data Collection procedure

The data were collected by using in-depth interview technique with semi structured interview guide. The interview guide was developed by reviewing literature considering the context of the study. To maintain consistency the tool was translated from English to Amharic. The interview guides include Socio-demographic characteristics of the participant and experiences related to hemodialysis. In-depth Interviews was conducted by investigator.

Notes and audio records of the interview were done during the interview. Probing was used to ensure the depth and clarification of the information provided during the interview.

Interviews were conducted based on the appointment date identified from the registration-book. The patients were invited to participate in the study before the dialysis. During the interview the place was convenient which means, in a private location with no outsiders present and where people feel that their confidentiality is protected. As much as possible to the participants to assure both privacy and confidentiality. Of eight participants, five of them were interviewed in the hospital room arranged by the hospital hemodialysis center coordinators that they usually used to have rest with the center team members who were giving care to the patients admitted to the center. The rest three were interviewed in their home. Interviews were lasted on average 40 minutes. Data collection was stopped when information saturation was achieved, i.e., data was collected until no new information was emerged.

4.5. Trustworthiness

The trustworthiness of the study was maintained by considering the following criteria: credibility, dependability, transferability and conformability.

To assure dependability the chosen methodology, selection and recruitment of participants, data collection methods and the analysis process were thickly described. Detailed chronology of research activities and processes, data collection and analysis, emerging themes, categories or quotations were audited by advisors, colleagues and examined by other person who has experience on conducting qualitative research to assure dependability and conformability audit. To assure credibility investigator set aside personal experiences and presumptions to illustrate the true picture of participant's accounts (Bracketing mind). The investigator was taken adequate time with participants and study participants were approached friendly with no pressure and interviewed at most comfortable environment. The interviews were open ended and respondent was allowed to discuss the questions in an uninhibited manner while being guided to remain focused to the topic of interest. Appropriate probes were used to obtain detail information on responses. Some of the transcripts were coded by a colleague and compared for similarity and the analysis also examined by him. Member checking was done at the time of the conversation and at the end of each data collection; the participants were given a summary of what they have said in order for them to confirm that it is what they wanted to say. To assure transferability the study participants was selected purposively who

fulfilled the inclusion criteria. Furthermore, thick description of all the inquire process and findings was made so that any reader of the report will be able to use and researchers may replicate the study at other setting which has possibly similar conditions.

4.7. Data analysis

For data analysis, the record materials were transcribed verbatim in local language and then translated in to English by principal investigator. Field notes were incorporated within the transcription simultaneously. Coding was carried out through reading and re- reading the compile transcripts using qualitative data management software ATLAS.ti version 7.1.4. Before the actual coding begins, the transcripts were independently read by the investigator and research assistant (friend). Codes were organized to create categories and themes. The data was analyzed by thematic analysis. Finally, result was presented using major or theme and categories support by quotes to describe an overall essence of the experience. An inductive approach was implemented to identify theme and category.

4.8. Operational Definitions

Hemodialysis (HD): The process of using a machine to ultra-filter fluid and waste products from the blood by way of a catheter, fistula, or graft(10).

Home hemodialysis (HHD): Dialysis treatments for patients administered in the home setting(50).

Peritoneal dialysis (PD): The process of removing waste products and water from the blood by using the peritoneal cavity as a semipermeable membrane(50).

Renal replacement therapy (RRT): A type of therapy required when the kidneys are unable to remove waste products and excess fluids; the therapies include HD, PD, and transplantation(50).

4.9. Ethical consideration

Ethical clearance was obtained from the institutional review board (IRB) of Jimma University, institute of health sciences, and then by explaining the aim and its significance, a support letter to conduct this research was obtained from chief executive director of JMC. After explaining the purpose of the study informed consent was obtained from all participants before their participation. To ensure confidentiality the data collection and processing of the name of participants have been changed. The collected data was used only for the purpose

agreed with the participant and not shared with others also audio and transcripts were kept safe.

4.10. Dissemination plan

The findings will be presented to Jimma university department of Nursing. Recommendation based on the findings will be forwarded to the hospital staff and administrative offices and also town health office by using E-mail. The findings may also be presented in different seminars, meetings and will be tried to publish in a peer-reviewed scientific journal.

CHAPTER FIVE RESULT

5.1. Socio-demography characteristics of participants

This study included eight participants, six of whom were males, with a mean age of 45 years ranging from 29 to 62 years. Seven of the study's participants were married, and one was divorced. One participant had a bachelor's degree, one had a diploma, two were in high school, and two were in primary school. The participant lived with hemodialysis for 24 to 108 months. Eight of the participants received HD service two times a week.

Table 1 *Description of participant characteristics in JUMC HD center southwest Ethiopia, 2022.*

part icip ant	Age	Sex	Marital status	Education al status	Duration of HD in month	Frequency of dialysis in a week	Residence of participant far from HD center in Km
1	29	M	Married	9	24	2x	218
2	44	M	Married	8	24	2x	1.5
3	40	F	Divorce	8	48	2x	1.5
4	32	M	Married	10	24	2x	45
5	50	F	Married	Illiterate	24	2x	1
6	45	M	Married	Degree	84	2x	66
7	62	M	Married	Diploma	24	2x	253
8	56	M	Married	Illiterate	108	2x	66

Description of participants' response

The study's findings are summarized into five major themes and sixteen categories, which are as follows: - Perception and biological aspects of CKD, such as the perceived cause of CKD, Physiological and physical experiences of CKD and Seriousness of the disease. Challenges faced by CKD patients include financial constraints, social life, physical, loss of a job, fluid and diet restrictions and loss of sexual feeling. Emotional disturbance and consequences of CKD like depression and suicidal thoughts. Coping mechanisms, like religious practice and social support.

Table 2 Major themes and categories of the study finding conducted at JUMC HD center, 2022.

Major themes	Categories
Perception and biological aspect of CKD	<ul style="list-style-type: none"> ✚ Perceived cause of CKD ✚ Physiological and physical experience of CKD ✚ Seriousness of the disease
Challenges faced by CKD patients	<ul style="list-style-type: none"> ✚ Financial constraint ✚ Social life ✚ Physical ✚ Loss of job ✚ Fluid and diet restriction ✚ Loss of Sexual feeling
Emotional disturbance and consequence of CKD	<ul style="list-style-type: none"> ✚ Depression ✚ Suicidal thought
Diverse outlook towards the machine and care at dialysis unit	<ul style="list-style-type: none"> ✚ Getting relief ✚ Feeling of dependent.
coping mechanism	<ul style="list-style-type: none"> ✚ Religious practice ✚ Social support

Theme 1 Perception and biological aspect of CKD

This theme contains description of perception and biological aspect of chronic kidney disease in patients with hemodialysis. It has three categories: living with perceived cause of CKD, the physiological and psychological experience of CKD and the seriousness of the disease

1.1 Perceived cause of CKD

In the context of this study, perceived cause of CKD refers to patients on hemodialysis who have one or more chronic non-communicable diseases in addition to renal failure and believe that this non-communicable disease is the cause of the disease. Chronic kidney disease patients on hemodialysis, either initially or after they have been diagnosed with CKD, are found to have hypertension, diabetes, and cardiac disease. Some of the patients expressed that diseases like diabetes, hypertension, etc. were the causes of their kidney failure. They said that they had been aware of their disease (hypertension) a year before, but they were not practicing what the doctor told them to do and not to do; they were eating salt and also not going to the hospital at the time of their appointment. They thought that the kidney failure was due to these cases. The other also said that they discovered they had hypertension while being tested for other diseases.

A 29 years old male chronic renal disease patient explained it as,

"One day I got into an accident, and I came to Jimma and visited one clinic, where they did a lot of investigation for me and told me that I had caught hypertension (raised blood pressure) in addition to the injury. They gave me medicine and told me to come back after two months. However, I failed to go back to my appointment after two months. I took the medicine they prescribed for me, and I became at ease, but I became sick after two months. Then I went to the previous clinic, and they told me that my kidney had failed, and they gave me a referral, so I went to Addis Abeba. But if I took my medicine properly, I might not have this disease."

A 32 years old male hospital admitted patient said that

"Before 6 years the doctor told me that I have hypertension and a raised blood glucose level, and he insisted that I start the treatment. That time I said OK to the doctor, but I started the treatment two years later than I was told to do so. During this time, I was not controlling my intake of salt and sugar. Before two years I developed shortness of breath and vomiting of everything what I ate. The doctors in Agaro told me that I had caught gastritis, hypertension, a raised blood glucose level, and heart disease and referred me to Jimma Hospital. When I came here, they told me that my kidney was failing. I think that the cause for this disease is my not practicing what the doctor told me to do."

In addition to this one of the participant mentioned that he acquired hypertension in addition to renal failure after he started hemodialysis.

"After I started the dialysis they told me that my blood pressure was raised and that I should start the treatment. But earlier, before the dialysis, I didn't have any medical problem. For the past two years, I was taking medicine for hypertension, in addition to hemodialysis."

(A 44 years old male CKD patient)

1.2. Physiological and physical experience of CKD

The physiological and physical experience of CKD in this study implies that chronic kidney disease patients complain of different signs and symptoms because of the disease. At the beginning of the disease or after they recognize themselves as CKD patients, they manifest different signs and symptoms like problems with urination, body swelling, and vomiting due to the complications of the disease. The study participants stated that they normally passed urine three times per day, but after developing kidney failure, their frequency of urination

decreased to once per day. Still, some of them complained that they failed to urinate at all. They also mentioned that as the disease progressed, they experienced swelling and breathing difficulties.

A 45 years old, male patient explained as

"I used to urinate about three times a day, but this was reduced to once a day, and finally I fail to urinate at all. And my body started to swell, and I encountered a problem of suffocation."

A 29 years old male CKD patient also mentioned that

"At the very beginning of the disease, my feet began to swell; there was also vomiting and a feeling of pain after urination. As the disease progressed, all my body parts were getting swollen, and I encountered shortness of breath."

In addition to what the other participant mentioned above, one of the participants mentioned that at the very beginning of the disease she manifested sudden nose and mouth bleeding and loss of consciousness; when she woke up, she found her in the hospital.

"I had been abroad (in Saudi Arabia) when the disease started. During the start of the disease, while I was working, the blood was flowing through my mouth and nose, and I was sent to the hospital. There were Egyptian doctors who helped me in the hospital. I realized that I was in a hospital after being in a coma for about three days."

(A 40 years old Female patient)

1. 3 Seriousness of the disease

This category describes the seriousness of the disease as mentioned by study participants who are involved in this study. The complications of the disease, the lack of curable medicine, the lifelong treatment of the disease, the expensive nature of the treatment, and restricting them from participating in their social life are the conditions that make it too difficult to live with the disease and make the disease serious.

A 40 years old female patient mentioned that

"The kidney disease, "wolahi", is too bad. I don't have any word to express it; no one knows it except the one who was exposed to it. This is because it requires economic potential and someone to support you. It is a kind of disease that isolates you from your friends and your job."

A 56 years old male participant stated that

"The disease is very bad; neither has it killed you soon nor you will not be cured of it. I have never seen such a bad disease. It is difficult to be cured of it here in our country, Ethiopia."

Theme 2 Challenge faced by CKD patients

This theme contains descriptions of challenges faced by patients with chronic kidney disease because of the disease or hemodialysis. It contains six categories: financial constraint, social life, physical, loss of Job, fluid and diet restriction, and loss of Sexual feeling.

2.1 Financial constraint

In the context of this study, financial constraints refer to the costs of dialysis, medication, and other related expenses that impacted the CKD patients' finances. The patients who are on hemodialysis are challenged by the expenses for the dialysis service provided in the hospital, transportation service to go for hemodialysis, house rent, and other basic needs such as food. The respondents mentioned that they spent a lot of money for hemodialysis service, especially when the dialysis machine in the public hospital is not active. Moreover, they expressed their ideas; saying that the transportation and house rent fees challenged them when the dialysis machine did not function in their dwelling areas.

44 years old, male, participant said that

"I don't even think or bother about what I eat because I don't have the appetite. I only suffer from a shortage of money for dialysis, medication like heparin and fluid; because I already sold all my properties and I'm now living in a rent house that also made me to suffer a lot."

A 40 years old male participant explained that she stayed without dialysis for more than two weeks because of financial problem.

"When the dialysis machine that I found in Jimma Hospital was disabled, I stayed for 18 days without taking the dialysis. I couldn't go to Addis Abeba when other patients went there because of financial problems. The hospital staff and students contributed birr for me, and I went to Addis Abeba and stayed in a hotel. The dialysis was done privately, and I paid 1500 birr at a time. I stayed there for a long time, and I encountered a shortage of money in Addis because the money that I received was not enough for the dialysis, transportation, and hotel service."

One of the participants reported that she was not following the dialysis regularly because of shortage of money

"If I don't have money, I won't go to the hospital for dialysis. The workers from the hospital asked me why I missed the program, but why do I go there if I don't have the money? If I get dialysis on Friday, I will suffer for the next one. I also struggle with feeding myself and my children." (A 62 years old participant)

One of the participants who were admitted to Saudi Arabia said that at the beginning of the disease, the support from the part of the government in Saudi Arabia was far better than in Ethiopia, as there was full sponsorship for the treatment of this disease, unlike here in Ethiopia.

"When I was in Saudi Arabia, they told me that it was too costly in Ethiopia to treat this disease, and they were right. The treatment requires potential. I didn't think that this would happen here; if I had known that I might face this challenge here, I would have stayed there. It was the government that covered the cost of my treatment there in Saudi Arabia. There is what they call "Alelkeyr" welfare activity. There is an organization that helped you get up to transplanting kidneys, but here in our country they practiced it only by giving only food."

(40 years old Female participant)

2.2 Social life

In the context of this study, social life indicates that chronic renal failure and hemodialysis disturbed the patients' social activities that they were accomplishing during their normal time. Previously, those participants had their own social activities, but after they caught this disease, they stopped all activities or interactions in the community. As the participants mentioned, the disease by itself has an impact on their social life, like not going to visit the family when somebody dies, to go to "Idir," and also when there is a marriage program. And also because of the disease, the families of the patients are affected by economic crises, which make the patients lose acceptance and respect in the family. A 56 years old male patient who came from far mentioned that

"I simply move from home to the hospital. I couldn't go to "Idir" meeting, or if one died, I couldn't go to the burial ceremony, or visit one who was sick as I did before; I don't have the potential. This disease isolated me from the community."

A 44 years old male participant who reside in Jimma mentioned that

"This disease (kidney failure) has brought a lot of changes in my life. When I was healthy earlier, I was communicating with my friends in a good way, but now there is no one who asks me, even through the telephone. Of course, they helped me a lot at the beginning when I caught the disease, but now there is no one who calls to ask me. Friendship is only possible if you have something at hand and are healthy. It is a give-and-take process. However, now if someone comes to visit you, it is only to give you some money."

In addition to what others said, some of the patients lose their power in their home because of the disease that brings financial loss

A 45-year-old patient mentioned that

"You can't order or say something to the family members to do or not do something as you did before. This is because you are not an influential person in the family because of this disease. You pass everything off as if you didn't listen to it or else you just simply accept what is said by the family members. "When you had money, you could bring something for the family and order or tell something to be done, but now you can do anything except accept and obey other family members' orders."

2.3 Physical

Physical in the context of this study indicates that those patients affected by this disease get tired easily. Patients who are on hemodialysis become easily tired when they work their usual activities which they perform easily when they were healthy; and this happens due to the condition of the disease. The tube which is inserted into their arms also limited them to do what they want. One of the participants mentioned that he couldn't even lift five liters of water and move from place to place after he had caught this disease.

A 56 years old male patient stated that

"I was living by working in my own mini café, "shay bet," after I encountered this disease; I couldn't even lift 5 liters of water. I feel tired easily; I can't perform my usual activity. If someone says, "I'm doing my job or any activity while on dialysis," it's a lie; or he/she may do office work, even if he/she claims it's just to go to the office, it's only for attendance because he/she couldn't sit for a long time."

A 29-year-old male patient who came from the district and stayed in a rental house for dialysis purposes said that

"I rented a home close to the hospital for dialysis purposes. Even if I'm close to the hospital, sometimes I can't walk. I feel weak and am even challenged to breathe when I go from home to the hospital for dialysis. I sit after taking some footsteps."

He also stated that

"Before, as I am a mechanic, I worked by going here and there where I was asked; I wash my own clothes, but now I can't do that easily; I feel tired, and also the tube that is placed in my hand makes me uncomfortable." (A 29 years old male participant)

2.4 Loss of Job

In the context of this study, loss of job refers to the inability to work the previous job that they were working to run their life. Most of the participants who are on hemodialysis were not able to return to their previous work because of the disease. This makes the participants think about the fee that they pay for dialysis and also about their future lives. The participants also mentioned that they were hard workers before, but because of this disease, they are not able to perform their previous job.

"Before, I had a car to lead my family's life. But now I have stopped working on the car because the disease does not allow me to work. As you can see, my body has become swollen, and sometimes I feel congestion; I even sold the car itself. Therefore, now I have nothing at hand, and as a result, life has become difficult for me." (A 44 years old male participant)

A 40 years old female patient mentioned that

"I used to be a hard worker, but the disease has made it impossible for me to do so. If the government sponsored me for the treatment, I could do my best for my life with the money that people give me."

"I was leading my life by working in my own shop. But, due to repeated follow-ups and the severity of the disease, I've stopped working and am now spending my time in the hospital."

(A 32 years old male participant)

2.5 Fluid and diet restriction

In the context of this study, fluid and diet restriction implies that CKD patients do not eat and drink as usual due to fear of disease progression. Patients on dialysis are not able to drink and eat fluids and food because of fear of the complications of the disease. Since they are not able to urinate, the pain and suffocation will be worse if they drink and eat what they find. Some participants stated that they restrict their intake of food and fluids because they believe that eating and drinking will worsen their suffocation until dialysis.

A 44 years old male patient stated that

"I will be limited to eating food and drinking water because if I eat and drink like I did before, I will suffer for the next two or three days after the dialysis. To be at ease from the congestion I limit myself from fluid"

"Sometimes, when I go to different woredas to collect money from people, I stop eating and drinking because if I get enough money, I will pass my dialysis appointment day. So, I manage myself by not drinking and eating." (A 29 years old male patient)

2.6 Loss of Sexual feeling

Loss of sexual feeling, in the context of this study refers to loss of sexual interest with their wife or husband. Loss of sexual feeling is one of the causes of divorce for patients who are on hemodialysis. Patients who are on hemodialysis have a loss of sexual feeling due to their disease condition or dialysis. This also makes it difficult for the participants to live with their life partners. The participants also mentioned that they lost sexual feeling after being diagnosed with this disease.

44 years old married participant mentioned that

"He dawn his head and clasped his hands together... After you got this disease, what you do for family will be cut off, and you can't perform something expected of you. It is difficult for example you may lose your sexual feeling, it makes your sex feeling zero. Your wife expects what is required from you; she is not actually a maid servant. So, if you won't do what is expected of you, it affects your mind/mentality."

"It may be either from the machine or the disease itself that I don't have any sexual feeling. If I want to make sex, I should eat a nice food and I should be relaxed, this may be once in a month." (A 56 years old male participant)

Theme 3 Emotional disturbance and consequence of CKD

3.1 Depression

According to this study depression implies that the patient with hemodialysis feels sad and loss of interest for activity and hopelessness because of different reasons. Chronic renal disease patients feel sad when they think that the disease is untreatable and also when they think for the service fee for the next dialysis. Some of the participants mentioned that when they think about their next appointment, their mood changes because they think from where they will get the money.

A 29 years old male patient mentioned that

"This disease makes you loss hope. For instance, there are people living with the disease for 10 or 12 years, and you don't see or hear that any one cured of this disease. If you see or hear that one is cursed of the disease, you may live with a hope. You may lose hope when one tells you that he/she is living for 10 or 12 years with the disease by begging people".

"Until I know, I am taking the dialysis with the money I saved in the bank by selling my car, but I am suffering from what will happen when the money is finished."

(A 44 years old male patient)

A 40 years old female participant mentioned that

"I feel a lot of things; For example I took the dialysis yesterday and I feel good for today and tomorrow, but after that my behavior will be changed, I feel depressed when I think for the next dialysis suffering from where I can get the money."

"The disease doesn't have a cure. If you don't go abroad for the treatment, you won't have hope to be cured here. Sometimes I feel sad when I think that I will live with the dialysis."

(A 62 years old male participant)

3.2 Suicidal thought

In the context of this study, suicidal thoughts imply that patients who are on hemodialysis attempt suicide. Most of participants prefer to commit suicide because of unaffordable expense for dialysis service and medication; and also loss of hope to be cured from the disease due to the un treatability of the disease.

A 44 years old male patient mentioned that

"At the very beginning of the treatment, many people can help you by contributing money for you. But after that, even your family gets exhausted trying to help you because you always expend money for the treatment and they will ignore you. Look, when I was in Addis Abeba, I begged the doctors to kill me by giving me medicine, and I told him that I would sign a document stating that it was done voluntarily... head dawn and sob... "It is difficult;" he said repeatedly...This is because managing a challenging life as a family holder is too difficult."

"When I start a dialysis, I lose hope because it requires money. When I finished money from my pocket, I will think to commit suicide." (A 32 years old participant)

A 62 years old participant mentioned that

"When the disease accelerates, you feel like committing suicide, but after the dialysis, you become normal."

Theme 4 diverse outlook towards machine and care at dialysis unit

This theme contains descriptions of the participants' experiences during hemodialysis and the care they have received in the dialysis unit. It contains two categories: getting relief and feeling of dependence.

4.1 Getting relief

Getting relief in the context of this study implies that the majority of the participants describe a good feeling towards the dialysis because it reduces their suffering from pain caused by renal failure and makes them relax for some more days. Most of the participants mentioned that the dialysis machine gives them relief from the suffocation that comes from the disease. They also described the importance of the machine and the care they received from the health professionals, saying that this was the only alternative for them to survive.

A 40 years old female participant mentioned that

"After 30 minutes of my taking the dialysis, I feel very happy; I just fall dead asleep. I believe that if things continue in this manner, my appetite will be fine and I will eat with pleasure. The thing that suffocated me will be gone, and I thought that there was no one in the universe happier than me."

A 50 years old female participant also mentioned that

"I didn't have any word to say about this machine, because for a delivery there is a doctor who can help you; if you are bleeding, you can get a cure or surgery. But for a kidney disease, there is nothing else for you other than dialysis."

"When I got the dialysis service, I felt at ease, and when the dialysis service was interrupted, the discomfort and the illness began to exacerbate. Then it became normal when I took the dialysis." (A 45 years old male participant)

One of the participants mentioned about the care she received in the dialysis unit

"The nurses there are very good for me; they do not degrades me. When I sometimes vomited, they treat me well and encourage me. They clean and change my clothes; they give me water

to drink and food when I sometimes speak to them with strong words, they jump as if they didn't hear me. They are very good persons." (A 40 years old female participant)

4.2 Feeling of dependent

In the context of this study, feeling of dependent means the feeling of some of the patients who believed that their survival depended on the support of the machine. Some of the participants described their feelings towards the machine, saying that if they stopped using the dialysis, they may develop suffocation and fatigue. Others have stated that they will not survive for a few days unless they undergo dialysis.

A 40 years old participant mentioned that

"It would be great if it were a disease that could be cured with pills, but it requires dialysis." A fish can't live out of water; it will die when it is out of water, and the same is true for me if I don't go on dialysis. So I should go twice a week, and I sleep on the couch for about four hours."

A 62 years old male participant also mentioned that

"It is difficult to live without getting dialysis, by any means if you miss the dialysis schedule you become congested so fearing of this, I come on the schedule".

Theme 5 Coping mechanism

This theme refers to what participant did to cope with the level of their illness and the challenge they face while they were hemodialysis. The respondent described two coping mechanisms some of them cope by religious practice and support provided by others

5.1 Religious practice

In the context of this study religious practice means that the study participants practice different religious activities to cope up with the consequence of the disease. Almost all of the participants believe that they obtain such treatment from the HD service is God blessing. Since the disease is serious, it requires income and curable medicine. They give their sole to God and waited the future by following the dialysis. They tried to use their faith as a source of coping up mechanisms while they live with the stress related to complications of the disease.

A 29 years old male participant stated that

“When I heard that my kidney is failed, I went to a holy place “tsebel” because I know the disease is untreatable and the only choice is that dialysis which I can’t afford. So, I went to “tsbel” and I was in a good health condition but when I came out from the holy place the suffocation exacerbates and then I came to dialysis. Now drink tsebel (holy water) with dialysis”

“At first I become hopeless; I was suffering from dying today or the other day. I have never thought of staying for these 4 years. I didn't think that I will stay even for 4 days leave alone for 4 years. Thanks to God I'm still alive by praying.” (44 years old male participant)

A 45 years old male participant mentioned that

“Always I pray to God to make me free from this disease because it is not treatable disease”.

One of the hemodialysis patients mentioned how her condition prevented her from taking part in an annual spiritual activity.

“I couldn't have face with the people during" ED" salat time because the disease suffocates me.”

(A 40 years old participant)

5.2 Social supports

The support that patients receive from their social circle influences their health outcome. CKD patients who have high social support have good hopes of surviving and are waiting for the future. The participant indicated that the support they are getting from their family and community makes them happy and makes them think that they are extending their life

A 40 years old participant said that

"One day in the past, a person dialed me and asked me if I'm Semira, and I told him that yes, I am. He told me to meet me, and he came to where I was, encouraged me, told me that he was by my side to help me, and gave me 10,000 birr. He told me to dial him if I face a problem in the future, and he went away."

A 45 years old patient also mentioned that

"It is my wife who encouraged me. The other thing is that there are a lot of people who encourage me because they feel that's what it would be like when I stop working and stay at home because of the disease. It is good if my relatives and friends will be with me and support me when I stay at home."

In addition to what other said a 56 years old participant mentioned that

"It was me who was working and helping the family earlier, but when I was sick and unable to work as usual, I handed over the work to my wife, and now she is the only one who is running the work, supporting the family, and covering my hospital fee as well."

CHAPTER SIX

Discussion

This qualitative study aimed to provide in-depth insights about the experience of chronic renal failure patients who are on hemodialysis in Jimma medical center. This finding shows that most CKD patients appreciate the important role of hemodialysis which plays a role that filters waste, removes extra fluid and balances electrolytes and that replaces kidney function. However, the patient experience different socio-economic challenges due to this disease.

Patients who are on hemodialysis in addition to chronic renal disease they suffer with chronic non communicable disease. The participant explained that initially or after they have been diagnosed with CKD is found with hypertension, diabetes and cardiac disease. Some of the participants expressed that condition of diseases like diabetes, hypertension, etc. could be causes for their kidney failure. The participant also discussed about the main sign and symptoms that acquire while the starting of the diseases and when the disease become worse or extend. As the participant indicates they manifest different signs and symptoms like problem of urination, body swelling and vomiting due to complication of the disease. This implies that the causes for the disease could be the patient not practice what the doctors told them to do for the non-communicable disease due to this the patient manifest different sign and symptom. The findings of this study in line with the study conducted in Tesfa(Association for Kidney) which is based in Addis Ababa(40).

This finding shows that, seriousness of the disease is mentioned by the participants, The conditions that makes too difficult to live with the disease were worsening of the disease even if there was a good adherence for the treatment, lifelong treatment of the disease, unknown of the future, restricting them from participating in their social life and their daily activity, expensive nature of the treatment, and the restricted intake of the meal. These finding supported by the studies done in Felege-hiwot comprehensive specialized hospital (41).

In this study participants were mentioned different challenges, financial constraint is one of the challenge raised by the participants. Financial constraint is a big deal for participants to have hemodialysis service. The expenses for dialysis service provided in the hospital, transportation service to get hemodialysis, house rent and other basic needs such as food were the common reason for the financial constraint of the patients who are on hemodialysis.

They also reported that social life, physical weakness, loss of job, as a challenge while they are on hemodialysis. The participants noted that the disease by itself has an impact on their

social life like not going visit the family when somebody dies, “Idir” and also when there is marriage program. The study participant also stated that Patients who are on hemodialysis become easily tired when they work their usual activities which they perform easily when they were healthy; and this happens due to the condition of the disease. This implies that CKD patient with hemodialysis may face different challenge due to the disease and HD. This is supported by a study done in Bahirdar and Nigeria which revealed that financial constraint is one of the challenging issues that prevent participants from accessing HD service (41,42). And also due to the chronicity of the disease and the nature of treatment process they are hindered from actively involved in social activities. Therefore, the patients face social decline as the result of the disease(43,44). Other study reviled that the progression of the disease and the nature of treatment impacts patients to make changes in relation to their employment(45).

In this study participants were mentioned fluid and diet restriction as a challenge. The participant noted that they were eating food and fluid without restriction but after they encountered this disease they restrict themselves from food and fluid. This implies that the compelling force to adhere to fluid and diet restrictions was another aspect which made the participants to perceive their lived experience as hard pressed (47,56).

In this study, it was found out that Spirituality as a challenge. According to the participant involved in this study they feel discomfort when they accomplish their day to day spiritual activities. This study supported by the study done in Jordanian patients reviled that patients who are on hemodialysis conveyed as unable to preserve their spiritual and ethnic customs resulting from, lack of energy, fatigue, leg cramps(44).

Regarding emotional disturbance; depression is the most emotional disturbance mentioned by the study participants. The participant mention that feel sad when they think that the disease is untreatable, due to loss of job and sexual feeling and also when they think for the service fee for the next dialysis. The participant also reported that they prefer to commit suicide because of different loss and unaffordable expense for dialysis service and medication. This study supported by the study conducted in Athens and London (48,49).

Patients who are on hemodialysis described different feeling towards hemodialysis and the care they have received from the health professionals. They explained that the dialysis machine gives them a relief from suffocation that comes from the disease. Some of the patients believed that their survival is depended up on support of the machine. This study

supported by the study conducted in Indonesia and Addis Ababa reported that the dialysis machine was perceived by the CKD patient in different way, some of them believed as the machine were an important instrument for supporting the life of the patient and the patient can't sustain without it (37, 39).

Participants in this study mentioned that religion and social support as a coping mechanism. Since the disease is serious and requires income they tried to use their faith and the support they are getting from the family and community as a source of coping mechanisms while they live with the stress related to complications of the disease. This finding in lined with the study conducted in Ethiopia, Canada and America (51–53). Patients with higher social support And also faith in God and prayers for healing are important element that contributes to the patients' survival and coping mechanism.

Strength and limitations

One of the strengths of the present study was that it involved participants from different socio-demographic backgrounds on the experience of chronic kidney disease. The second was that the study employed respondents with rich experiences in the area of study. Third strength was that the interview questions were open-ended so that they allowed participants to tell whatever they felt without restriction.

The limitation of the study was that the study was conducted in one hemodialysis center the findings of this study does not represent other hemodialysis center.

CHAPTER SEVEN: Conclusion and recommendation

7.1. Conclusion

Five major themes are emerged from the participants' interviews. This study provides understanding experiences of chronic renal disease patients who are on hemodialysis in JMC.

The study found the perception and biological aspect of CKD like perceived cause of CKD, physiological and physical experience and seriousness of the disease. It explored challenges faced by CKD patients include financial constraint, Social life, physical, loss of job, fluid and diet restriction, and loss of sexual feeling. Emotional disturbance and consequence of CKD like depression and suicidal thought are revealed in this study. Diverse outlook towards the machine and care at dialysis unit are; getting relief and feeling of dependent. This study also explored coping mechanism like religious practice and social support.

From this it is possible to conclude that financial constrain is the main challenge faced by CKD patients which deteriorate their life. Challenge to obtain the service and they are obliged to live with the support of others and due to the nature (seriousness) of the disease the patients hindered from actively involved in social activities and previous work. Due to this the patients think that the disease is serious and thinks to committed suicide.

7.2. Recommendations

- The Ministry of Health, Oromia regional and Jimma town health bureau should promote the prevention of CKD.
- Ministry of Health and regional health bureau and other stakeholders should give attention on the means of supporting or decreasing the costs of dialysis and medications up to making it for free through health insurance coverage.
- The hospital administrators should assign psychologists to provide counseling for each patient who attended on HD center.
- The hospital and the town health bureau, by involving stakeholders and charity organizations, make free transportation and food service for patients who are on hemodialysis.
- Other researchers are better to conduct further study on lived experiences of patient who are diagnosed as CKD but who did not yet start HD therapy and the lived experience of health professional who are working in the hemodialysis unit.

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**ANNEX-I-ENGLISH VERSION DATA COLLECTION TOOL
PARTICIPANT I
INFORMATION SHEET AND CONSENT FORM**

**JIMMA UNIVERSITY, INSTITUTE OF HEALTH SCIENCES, FACULTY OF
HEALTH SCIENCE SCHOOL OF NURSING AND MIDWIFERY**

Project title: Lived experience of chronic renal disease patient who are on hemodialysis: phenomenological study at Jimma university medical center, south west, Ethiopia, 2022

Name of the organization: Jimma University **Name of the sponsor:** JUMC

Instruction: please read a copy of the full informed consent form to the respondent

Introduction:

Information sheet prepared for chronic renal failures (CRF) that are on Hemodialysis and prior to the study to participant in this research project. The research group includes principal investigator (data collector).

Purpose of the research:

To explore lived experiences of chronic renal disease patients receiving hemodialysis in Jimma university medical center, Jimma city and the information of this study will be useful for effective health interventions. The study was carried out for one month.

Benefits, Risk and Discomfort:

Your participation will help us to find more about CRF patient experience and this will help to improve hemodialysis service in the city. There is no risk or direct benefit in the participating in this research.

Incentive:

We will not pay you for taking part in this study.

Confidentiality:

The information that we collected in this study will be kept confidential by using codes instead of any personal identifiers and is meant only for the purpose of the study.

Right to refuse or withdrawal:

You have the full right to refuse and have the right to discontinue the interview at any time, and refusing to participate will not affect anything you want.

Consent form

My name _____ and I am collecting data for the research being conducted by Mss. TINSAE SEMU, Masters Student from Jimma University. She is doing research on CRF patient who are on Hemodialysis experience as the partial fulfillment for master's degree in Adult Nursing. You are selected to be one of the participants for the study. This interview probably takes few minutes. I would like to assure you that all you tell during the interview will be strictly confidential and that information collected from you used only in scientific reports without any mentioning of personal information including your name. There is no harm or incentive for your participation. Information gathered from the study will be used to improve programs that promote Hemodialysis service. If you have any question about this study you may ask me or principal investigator; Mss. TINSAE SEMU using his phone number +25191726514125 or his email Tinsaesemu7gmai.com.

II. Interview Guide English version

A. Socio demographic character of participant

1. Age
2. Sex
3. Marital status
4. Educational status
5. Occupations
6. Source of income
7. Monthly income in birr
8. Year of CKD diagnoses
9. Year of hemodialysis initiation
10. Frequency of hemodialysis in a week
11. Cause of the disease

B. Interview guide

1. What is your role in the family and social situation?
2. How do you express chronic renal failure?
3. How do you express the feeling while you live with CKD?
4. What change CKD had brought to your life?
Probe: (daily activity, religious activity, social life, working aria)
5. What things that makes difficult to live with CKD?
Probe: (To accessing treatment, attend based on schedule)
6. What symptoms do you experience?
Probe: How do you express its feeling?
7. How do you express hemodialysis machine?
8. How do you express the feeling while you live with hemodialysis treatment?
Probe: What do you feel before, during and after the procedure?
9. What things that influence you to attend the dialysis schedule?
Probe: (cost, work place, your culture, interest of your family.)
10. What do you feel when you miss one schedule of dialysis?
Probe: (What is the reason to miss the schedule?)
11. How do you express the care that you receive in the unit?

ANNEX-III - In-depth Interview Guide Amharic Version

A. የተሳታፊዎች ሁለንተናዊ መገለጫ

1. እድሜ
2. ጾታ
3. የጋብቻ ሁኔታ
4. የትምህርት ሁኔታ
5. ስራ
6. የገቢ ምንጭ
7. ወርሀዊ ገቢ
8. ስር የሰደደ የኩላሊት በሽታ እንዳለብዎ ያወቁበት ጊዜ
9. የኩላሊት እጥበት የጀመሩበት ወቅት
10. በሳምንት ለምን ያህል ጊዜ የኩላሊት እጥበት የደርጋሉ
11. የህመሙ መንስኤ
12. የሚኖሩበት ቦታ

A. የቃለመጠይቅ መመሪያ

1. በቤትዎ እንደሁም በመህበረሰቡ ውስጥ ያለዎት ሚና ምን ይመስላል
2. ስር የሰደደ የኩላሊት ህመምን እንዴት ይገልጹታል
3. ስር ከሰደደ የኩላሊት ህመም ጋር መኖርን እንዴት ይገልጹታል
4. ስር የሰደደ የኩላሊት ህመም በህይወትዎ ምን አይነት ለውጥ አመጣ መርምር (በቀን ተቀን እንቅስቃሴዎ፣ በእምነት አገልግሎትዎ፣ በማህበራዊ ህይወትዎ፣ በስራ እንቅስቃሴዎ)
5. ስር ከሰደደ የኩላሊት ህመም ጋር መኖርን አስቸጋሪ ሚያደርገው ምንድን ነው (ህክምናውን ማግኘት አለመቻል፣ በቀጠሮት እለት አጥብቱን ለማድረግ)
6. ስር የሰደደ የኩላሊት ህመም ምን አይነት ምልክቶችን ያሳያል መርምር (የህመም ስሜቱን እንዴት ይገልጹታል)
7. የኩላሊት እጥበት መሳሪያውን እንዴት ይገልጹታል
8. ከኩላሊት እጥበት ህክምና ጋር መኖርን እንዴት ይገልጹታል (እጥብቱን ከማረጋገጥ በፊት፣ በሚያረጋገጡበት ወቅት እና ካረገ በኋላ ያለውን ስሜት እንዴት ይገልጹታል)
9. የኩላሊት እጥበቱን በ ቀጠሮዎት መሰረት እንዳያከናውኑ የሚያስገድድዎት ምን ይሆናል ብለው ያስባሉ መርምር (የእጥበቱ ዋጋ፣ የስራ ጫና፣ በህል፣ የቤተሰብ ፍላጎት)
10. አንድ እጥበት ሳያደርጉ በሚቀሩበት ወቅት ምን ይሰማዎታል መርምር (በምንስ ምክንያት ነው የሚያቋርጡት)
11. በኩላሊት እጥበት መከሰቱ የሚያገኙትን አገልግሎት እንዴት ይገልጹታል

DECLARATION

I, the undersigned, declare that this thesis is my original work, has not been presented for a degree in this or any other university and that all sources of materials used for the thesis have been fully acknowledged.

Name of investigator: Tinsae Semu Signature Tinsae

Name of the institution. _____

Date of submission. 03/05/2015

This thesis has been submitted for examination with my approval as University advisor

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