



SEEK WISDOM, ELEVATE YOUR INTELLECT AND SERVE HUMANITY !



**Gratitude for living off a machine: Lived Experiences of Patients
Aged 18 to 40 years with chronic kidney disease on Hemodialysis
Treatment: A phenomenological Study**

**By:
Yonatan Bekele (B.SC in Public Health) GSR/5970/16**

**A Research Thesis Submitted to the Graduate Program of Addis
Ababa University, College of Health Sciences, School of Public Health in
Partial Fulfillment for the Degree of Masters of Public Health with
specialty in General Public Health**

**Addis Ababa, Ethiopia
June, 2025**

Addis Ababa University
College of Health Sciences
School of Public Health

Gratitude for Living Off a Machine: Lived Experiences of Patients Aged 18 to 40 years with chronic kidney disease on Hemodialysis treatment: A phenomenological Study

By:

Yonatan Bekele (B.SC in Public Health) GSR/5970/16

Advisors:

Professor Mitike Molla (PhD)

Kalkidan Solomon (PhD candidate)

A Research Thesis Submitted to the Graduate Program of Addis Ababa University, College of Health Sciences, School of Public Health in Partial Fulfillment for the Degree of Masters of Public Health with specialty in General Public Health

Addis Ababa, Ethiopia
June, 2025

APPROVAL SHEET

**ADDIS ABABA UNIVERSITY,
COLLEGE OF HEALTH SCIENCES
SCHOOL OF PUBLIC HEALTH**

**Gratitude for living off a machine: Lived Experiences of Patients
Aged 18 to 40 years with chronic kidney disease on Hemodialysis
Treatment: A phenomenological Study**

BY

Yonatan Bekele (B.SC in Public Health)

Approved by the Examining Board:

_____	_____
Chairman, Dean of School of Public Health	
_____	_____
Advisor	
_____	_____
Internal Examiner	
_____	_____
External Examiner	
_____	_____

Acknowledgement

In this journey called life, I only acknowledge God as my strength, support and provider. Throughout this journey, through the battles and victories, in all the sorrow and joy, God has been there and was the only constant. I thank God for being God and for all the help.

I would also like to extend my deepest gratitude to my mother, who has been by my side supporting me in every aspect of life. This is for her.

Friends and family, for the love shown, for the support given, I am deeply thankful.

I would also like to extend my gratitude for my advisors Professor Mitike Molla (PHD) and Kalkidan Solomon (PhD candidate) for their mentorship and unwavering support and dedication. Addis Ababa university, College of Health Sciences, School of Public Health, has provided me with this opportunity to gain knowledge and participate in this prestigious program, for which I am very grateful. I would also like to extend my gratitude towards all the participants who participated and gave their honest opinion as well as data collectors for their dedication.

Contents

Acknowledgement	iii
List of tables.....	viii
List of Acronyms and abbreviations	ix
Introduction.....	1
Background	1
Statement of the problem	2
Rationale for conducting this study	3
Significance of the study.....	4
Research questions	5
Literature review	6
Global burden of CKD and Hemodialysis	6
CKD and Hemodialysis in Ethiopia.....	7
Factors associated with undergoing hemodialysis	8
Medical and physical factors.....	8
Psychological and emotional factors.....	9
Health care related factors.....	10
Financial constraint	10
Impact of hemodialysis on quality of life	11
Coping mechanisms of young adult patients undergoing hemodialysis	12
Objectives.....	14
General objectives.....	14
Specific objectives	14
Materials and methods.....	15
Study setting and period.....	15

Study approach.....	16
Population	16
Study participants.....	16
Recruitment of participants.....	16
Data collection methods.....	18
Data processing and analysis	18
Trustworthiness (Rigor)	20
Reflexivity.....	21
Operational definition	21
Ethical considerations	21
Dissemination of the results.....	22
Results.....	23
Socio-demographic characteristics	23
Hemodialysis experience	24
Physical and emotional experience	24
Financial experience	24
Availability, accessibility and efficiency of healthcare	25
Experiences associated with caregivers	25
Treatment Experience and Health Status of Hemodialysis Patients	26
Perceived Effectiveness and Gratitude for Treatment	26
High prevalence of comorbid conditions.....	26
Underlying causes and secondary diagnoses	26
Lifestyle modifications	27
Treatment adherence	27
Diet and nutrition	29

Interaction with healthcare workers	30
Challenges and coping mechanisms	31
Physical and emotional challenges	31
Economic challenges	32
Social challenges	32
Coping mechanisms	32
Perception of health care providers	33
Health care providers view on patients' challenges	34
Challenges in providing dialysis	34
Support	35
Accessibility and affordability	36
Opinions from patients	36
Discussion	38
Strength and limitation of the study	45
Strength of the study	45
Limitation of the study	46
Conclusion	47
Recommendations	48
References	49
Annexes	58
DECLARATION	58
Annex I: participant information sheet and consent form	59
Annex II: Consent form	61
Annex III: Verbal consent form	62
Annex IV: English version of the questionnaire	63

Annex V: Amharic version of the consent forms and questionnaire	65
Annex VI: Consolidated criteria for reporting qualitative studies (COREQ) checklist	70
Annex VII: Code Book.....	72
Annex VIII: Curriculum vitae of the primary investigator	74

List of tables

Table 1: number of patients selected centers provide dialysis for (recruitment of participants) ..	17
Table 2: sampling of targeted participants.....	17
Table 3: table of the description of the coding tree.....	18
Table 4: Socio-demographic characteristics of participants	23
Table 5: COREQ checklist.....	70
Table 6:code book.....	72

List of Acronyms and abbreviations

AA	Addis Ababa
AAU	Addis Ababa University
AKI	Acute kidney injury
ASMR	Age-standardized mortality rate
CKD	chronic kidney disease
COREQ	consolidated criteria for reporting qualitative research
DALYS	Disability adjusted life years
DCs	Data collectors
ERB	Ethical review board
ETB	Ethiopian Birr
GBD	Global burden of disease
HD	Hemodialysis
IDI	In-depth-interview
KDIGO	Kidney disease improving global outcomes
LMICs	low- and middle-income countries
PHCUs	Primary health care units
PI	Principal investigator
QOL	Quality of life
RRT	Renal replacement therapy
UNECA	United nations economic commissions for Africa
USD	United states of America Dollar
WHO	World Health Organization

Abstract

Background : Chronic kidney disease (CKD) affects about 12.1% of the global population where the prevalence is higher in Africa at 15.8% (2018). In Ethiopia, the prevalence of CKD was 12.2% where the prevalence among adults aged 35 and less was estimated to be around 41% in 2018. CKD progress to end stage renal disease (ESRD) where patients will be forced to undergo dialysis or kidney transplant. With the latter being difficult to access, most patients will be put on dialysis. Dialysis interferes with daily life, causing feelings of isolation, depression, frustration apart from its high cost. Despite these challenges, in Ethiopia, little is known about the lived experiences of patients who are living with CKD especially at their productive age.

Objectives: To explore the lived experiences of patients aged 18 to 40 years old, with chronic kidney disease on hemodialysis treatment.

Methods: phenomenological qualitative research was employed to explore the lived experiences of dialysis patients. Data were generated using a semi structured in-depth interview guide among 17 purposively selected participants. The interview was then transcribed verbatim and translated to the English language and coded using open code software version 4.03 and data were analyzed thematically. Efforts were made to uphold the qualitative study's credibility, dependability, transferability, and confirmability.

Results: Six major themes and 12 sub-themes emerged from the data. This study showed that adults aged 18-40 years face unique burdens while undergoing dialysis including career disruption and social alienation, physical changes, emotional challenges such as depression and anxiety. In addition, the need for adaptive strategies centered on peer networks, self-discipline, and external support systems were eminent findings.

Conclusion: The findings revealed complex interplay of physical, emotional, economic, and social struggles, and coping mechanisms of patients. Following the findings, a shift from clinical management to a holistic approach addressing the physical, social, emotional and financial needs, need to be put in place.

Key words: chronic kidney disease, hemodialysis, lived experiences, young adults, Ethiopia

Introduction

Background

The world health organization (WHO) together with, Kidney disease improving global outcomes (KDIGO) defines chronic kidney disease (CKD) as “abnormalities of kidney structure or function, present for a minimum of 3 months, with implications for health.”(1). There were more than 850 million people diagnosed with kidney disease globally in the year 2019(2). The overall prevalence of CKD in Africa in the year 2018 was 15.8% while in eastern africa it compromised about 14.4%(3). In recent years, chronic kidney disease (CKD) has become a growing health concern, contributing to higher rates of illness and death worldwide(4). There are two main treatments for CKD: kidney transplant and hemodialysis(5).

Dialysis is the main modality of treatment for severe kidney disease due to shortage of organ donors and high transplant risks. Dialysis helps to prolong life of patients(6). There are three types of dialysis including home hemodialysis, in-center hemodialysis and peritoneal dialysis. Of which the focus of this study was in-center hemodialysis. Dialysis in general is a way of replacing the impaired filtration function of the kidneys with machine filtration. A standard practice of three dialysis sessions per week is advised for patients (7).

Though dialysis is known to support the lives of patients with CKD, it is not without risks. A study in Ethiopia found that 45.1% of patients died during dialysis, and 23.1% died within the first 90 days. Only 42.1% of patients survived more than a year. These statistics can be indicators of the many challenges patients on dialysis face(6). In addition to these, there are also evidences that show that dialysis imposes significant burdens, particularly for young adult patients. They must undergo regular treatment, each lasting several hours, which interferes with daily activities, education, and work. For young individuals, this routine can create a sense of loss of independence and frustration(8).

Adults with chronic kidney disease that are undergoing dialysis face serious psychosocial challenges, including depression, anxiety, and social isolation (9). They also often struggle with decision-making, which affects their mental and emotional well-being(10). Ethiopia, as a low-income country, faces significant challenges in healthcare due to limited resources. In such

settings, medical treatment, including dialysis, is often costly, and most patients must pay out of pocket(11). A study in Addis Ababa highlighted the high cost of dialysis and suggested that steps should be taken to make it more affordable for those in need(12).

Having all these burdens chronic kidney disease (CKD) is a growing health issue in Ethiopia, but there are limited evidences that show the experiences of young patients with CKD. Most studies focus on older adults or clinical outcomes, leaving behind the emotional, social, financial and physical challenges of young dialysis patients. This study aimed at exploring the lived experiences of young patients on hemodialysis.

Statement of the problem

Chronic kidney disease (CKD) is a major global health issue that places a heavy economic burden on healthcare systems. It affects an estimated 11 to 13% of the global population. The majority of these cases are in stage 3, which is considered moderate kidney damage(13). A 2017 report by the global burden of disease (GBD) ranked CKD as the 16th leading cause of premature death. It also estimated that in the year 2040 it will be among the top five leading causes of premature death(14).

In a meta analysis done, the global age-specific incidence rate of early-onset chronic kidney disease (CKD) in adults significantly increased. The rate rose from 25.04 cases per 100,000 populations (with a 95% confidence interval of 18.51 to 31.65) to 32.21 cases per 100,000(15). Although there are limitations on data about the prevalence of CKD, few studies indicate estimations of around 12.2% prevalence among young populations aged 18 to 40 years of age, CKD prevalence is as high as 41.0% in those under 35 years, with 62% of cases occurring in males(6).

Routine hemodialysis is very stressful, has a tendency to lead to depression, poses a threat towards developing anxiety and reduces quality of life of patients. Hemodialysis patients have to sometimes travel long distances three days a week to have a three to four hours long sessions. This has an inhibiting factor for patients to obtain regular jobs, maintain relationships and it induces physical and mental disorders(16). In Ethiopia, hemodialysis is a common treatment for chronic kidney disease (CKD). This has introduced additional burden to the already overburdened health system of the country. Hemodialysis is often unaffordable and inaccessible for most patients.

Without taking into consideration the costs of medications for comorbidities such as medications from anemia, bone disorders, hypertension, diabetes, the cost of dialysis solely was estimated to be around 2300 Ethiopian Birr (Equivalent to USD\$51) per session according to a study done in the year 2022 (17). A price that has surged up since.

Despite the rising number of adults with CKD in Ethiopia, there is limited research on the unique challenges these groups face. The emotional, social, financial and physical challenges faced by them are not well understood. Most studies focus on clinical outcomes, leaving a gap in knowledge about how young patients cope with their illness. These individuals often struggle with depression, anxiety, isolation, and the high costs of treatment which have not been studied exhaustively. There hasn't been any initiation towards mitigating the different challenges and problems faced by these patients, by the government or other stakeholders, locally as well as nationally.

The lack of research on the challenges faced by adults aged 18-40 years with CKD in Ethiopia leaves a gap in understanding how the disease affects them beyond just their physical health. These individuals face emotional, financial, and social challenges as well that are not fully addressed in current studies. To improve care for young CKD patients, it is important to explore these issues and provide support that considers their overall well-being, not just their medical treatment.

Rationale for conducting this study

Most research on CKD focuses on older adults and their clinical outcomes, but there is little information about the challenges faced by younger adults, aged 18-40. These patients face unique challenges while undergoing dialysis which significantly differs from those faced by older patients. This age group is often going through important life stages like finishing school, starting careers, or building families. The impact of dialysis on these transitions is often overlooked in research, rendering it necessary to explore how adults balance their personal, academic, social and professional lives while managing the physical and emotional demands of CKD. By focusing on this specific group, the study aimed at filling a significant gap in current knowledge.

Frequent dialysis treatments and the limitations of the disease can affect their energy, self-esteem and overall quality of life. Additionally, mental health issues such as depression, anxiety and

isolation can be exacerbated by the chronic nature of the disease. Identifying coping strategies and sources of social support is essential to help these individuals manage dialysis-induced distress. Tailoring healthcare practices to the unique needs of adults can improve clinical outcomes and emotional well-being, ensuring that their care is more suited for their specific stage of life. This study will serve as an important starting point for understanding the experiences of young adult patients with chronic kidney disease (CKD) who are undergoing hemodialysis in Ethiopia.

Significance of the study

The research will provide valuable insights into how young CKD patients deal with the social, emotional, financial and physical pressures of CKD and the stigma often linked with chronic illness. These findings will help healthcare providers better understand the needs of young patients and create care plans that address not only medical treatment but also their emotional well-being. Additionally, the study will highlight the need for better mental health services for young CKD patients, particularly in addressing issues like depression, anxiety, and social isolation. It could also influence healthcare policies by suggesting the creation of financial assistance programs to help with the high costs of treatment.

Results obtained from this study can also be used by different stakeholders to address the many issues these young patients face in their day-to-day life and activities. As one of the objectives of this study is to highlight the financial burden faced by dialysis patients in general and young dialysis patients in particular, different stakeholders can use the findings of this study to take appropriate measures and support initiatives aimed at alleviating the financial burdens imposed on these patients.

Research questions

1. How does being in the 18 to 40 age range influence the experience, perception, and physical health challenges related to hemodialysis, including symptoms of chronic kidney disease?
2. What coping strategies do individuals aged 18 to 40 use to manage the disruptions caused by hemodialysis, and how do they balance daily activities, work, education, and social life?
3. What emotional and mental health challenges do adults face while undergoing hemodialysis, and how do healthcare providers address any mental health issues that arise?
4. What are the roles of healthcare providers and the impact of social support on the overall physical and mental health of dialysis patients?

Literature review

Chronic kidney disease has been defined in many different ways over time. But the current international definition of CKD is presence of markers of kidney damage or glomerular filtration less than 60 ml/min/1.73m² for more than 3 months, irrespective of the underlying cause(18–20).

Global burden of CKD and Hemodialysis

A recent meta-analysis study in the year 2022 estimates that there are around 843.6 million people affected with CKD. The study also revealed that the global prevalence of CKD stages 1-5 to be 13.4%. it also reported a percentage of 10.6% prevalence for CKD stage 3-5(21). A more recent study revealed that the global median prevalence of CKD was around 9.5% with the highest number recorded in Eastern and Central Europe(22).

Other studies showed that there has been a surge in the incidence and prevalence of CKD over time. One study found an increase in the number of CKD patients from 7.8 million in 1990 to 18.99 million in 2019 with DALYS increasing from 21.5 million to 41.54 million(23). A study also put the age-standardized incident rate of CKD at 30.3% per 100,000 in 2019 which showed a 21.8% increase from the year 1990. The age-standardized mortality ratio (ASMR) was also recorded at 5.2 per 100,000 which showed a 24.6% increase from the year 1990(24). A similar study also found death associated with CKD showed a significant increase from 192.26 thousand in 1990 to 487.97 thousand in 2019(25). The above study also showed that Central Latin America exhibited the most ASMR recorded, followed by Southeast Asia and Andean Latin America. Whereas, Eastern Europe recorded the lowest ASMR due to CKD(25). With a prevalence rate ranging from 5-18%, the International Society of Nephrology's Global Kidney Health Atlas found the prevalence of CKD in Africa to be 6%(26). Another study found the pooled prevalence of CKD in Africa to be around 10% whereas prevalence in sub-Saharan Africa was found to be 14%(27). A study in Ethiopia revealed the prevalence of CKD among patients with chronic illness to be around 21.7%, with most of the patients coming from the Oromia region (32.55%)(28).

There are many causes of CKD. The primary causes reported however are diabetes and hypertension. According to the US CDC 1 in 3 and 1 in 5 of diabetes and hypertensive patients will end up being diagnosed with CKD respectively. Other causes of CKD include glomerulonephritis, Chronic tubulointerstitial nephritis, Hereditary or cystic diseases and so on. The causes of CKD in general can be classified as prerenal, intrinsic renal and postrenal diseases.

According to CDC's 2021 statistics those aged 65 and older (38%) were more prone to CKD, followed by those between 45-65 years (13%) and 18-44 years (7%), with CKD prevalence reported to be slightly higher in males than females (20,29). The percentage of prevalence of CKD reported among those aged 18-44 seems to be low when compared to those that are above 45 years old, however, it should be noted that these age groups are not supposed to be at risk of developing CKD as compared to older age groups. In addition, it is rare to see the comorbidities and factors such as diabetes and hypertension that are the primary causes of CKD in these group of people. Hence, this prevalence can be considered high, instigating need for further research on these groups.

There exist three treatment modalities for patients with CKD who need renal replacement therapy. The three modalities are kidney transplantation, hemodialysis and peritoneal dialysis. Although kidney transplantation is the best treatment modality with the best outcome for patients, because of scarcity of lack of donors most patients resort to dialysis(30). One study found that hemodialysis was the most common treatment modality (60%) followed by kidney transplantation (30%) and peritoneal dialysis (10%)(31).

Another study found that hemodialysis is the most common type of renal replacement therapy used worldwide with a prevalence rate of 69% of the general available renal replacement therapies(32).

One study found that chronic hemodialysis was available in 162 countries, with kidney transplant available in 116 countries. Only 121 countries provided hemodialysis for approximately 50% of their population who are affected with CKD(22).

CKD and Hemodialysis in Ethiopia

A cross-sectional study conducted in the year 2018 in Ethiopia estimated that 12.2% of the population suffer from CKD. Of these patients those aged 35 and below account for about 41%(33). Another similar study found the prevalence of CKD patients among chronic patients to be 21.3%(14).

With the highest prevalence recorded in Oromia region, a pooled estimated of CKD patients among chronic patients showed a 21.7% prevalence rate(28).

Renal replacement therapy (RRT) was first introduced in Ethiopia in the 1980's with hemodialysis as the flagship treatment modality. Its introduction was however, for those suffering from acute kidney injury (AKI). The treatment was started in a single public hospital. In the year 2001,

maintenance hemodialysis was introduced into the country and started providing dialysis for chronic kidney patients as well. Recently there has been a surge in the number of dialysis providing facilities across the country especially within the capital Addis Ababa(17).

One qualitative study in Ethiopia resulted in the following experiences among dialysis patients: Feeling grateful, facing a restricted life, a supportive environment, dreaming of a transplant, and leading a hassled life. These are some of the common themes among dialysis patients(34).

Factors associated with undergoing hemodialysis

Medical and physical factors

Fluid restrictions, special diets, regular trips to the hospital, unscheduled visits to the emergency unit, taking medications regularly are some of the challenges dialysis patients face. Adults suffering from CKD face a lot of challenges including the above-mentioned ones in maintaining their health. Adults are at a greater disadvantage and risk than other groups of CKD patients because of their age. Young adulthood is an age where people start to adopt to their body, find themselves, start careers, get themselves ready for relationships so on and so forth. The medical and physical factors such as fluid restriction, special diet, constant visit and stay in the hospital, change in physical appearance, hinders their movement, motivation to work, self-esteem.

A study in Addis Ababa highlighted the significant impact of physical restrictions on adults with chronic kidney disease (CKD) who are undergoing hemodialysis. The strict fluid and dietary limitations required for dialysis can be very challenging, leading to frustration, fatigue, and a reduced quality of life. In addition to these restrictions, the need for dialysis access lines and the complications they cause add further medical challenges, making daily life even harder. These factors contribute to the overall burden of living with CKD and undergoing regular dialysis treatments(34). Similarly, a study at Felge Hiwot Centralized Hospital found that patients with CKD often feel weak and tired, making it difficult for them to complete daily tasks or work. The physical strain from the disease, along with the need to manage strict diets and fluid intake, lowers their energy levels and productivity(35).

A study in Kampala, Uganda found that patients suffered from body weakness, fever, feeling hot, fatigued, inability to move, dizziness, loss of weight, inability to do work, difficulties in breathing, loss of energy, loss of appetite, menstrual irregularity, muscle and bone cramps and headache

associated with dialysis. Some of the participants also reported of having lost weight because of the fluid and diet restrictions(36).

Another study by Al-Talib, et.al also states that challenges faced by young dialysis patients undergoing dialysis include those of mental health including depression and anxiety as well as physical health as they balance life between hemodialysis and manage life goals such as career and relationships(37).

A study in Brazil revealed that managing fluid consumption and diet was a common challenge for both young adolescents and adults on hemodialysis. They struggled with controlling their weight between dialysis sessions, which added to the difficulty of maintaining self-care. These nutrition and fluid-related issues, along with the physical and emotional toll of CKD, make it hard for patients to manage their condition effectively and maintain a normal life(8).

Psychological and emotional factors

A meta-analysis among adults with chronic kidney disease (CKD) and those on hemodialysis found that these health conditions make it difficult for them to achieve their life goals. They often feel different from their peers, leading to loneliness, low self-esteem, and a sense of losing their identity. The ongoing health issues can leave them stuck in an "in-between" stage, where they can't fully move into adulthood. This delay affects their personal and social development, making it harder to grow and feel confident about their future(11).

Similarly, a study in Georgia found that young CKD patients often struggle with their self-image, feeling like their condition makes them "different" or "out of place." This can lead to a loss of confidence and motivation to pursue their life goals(38).

A study in Iran highlighted that patient on hemodialysis face significant psychological stress, with feelings of anxiety and depression. The lack of empathy from healthcare staff can make these emotional challenges worse. Family support, especially from a spouse, is key to helping these patients cope, but without it, they may feel more isolated. Many also experience social stigma, being pitied or seen as weak, which can further harm their mental well-being. Changing attitudes toward CKD patients in society could help improve their emotional support(12).

In two studies done in Brazil, adults with CKD reported feeling emotionally vulnerable, as the illness disrupts important life plans, such as careers, education, and starting a family. They also face stigma, which can increase feelings of isolation and stress. Supportive care and understanding from others are essential to help them manage these challenges(9,39).

Health care related factors

An Ethiopian study on global dialysis perspective states that challenges in provision of hemodialysis ranged from policy to lack of resources. The fact that renal care in Ethiopia is in a policy vacuum stakeholder are unable to work effectively making health care inaccessible. Provision of dialysis is largely left to the private sector and there is little to none quality check on these centers as well(17). A study assessing factors affecting access to dialysis in Sub-Saharan Africa found health provider-related factors, health system-related factors, and patient factors to be barriers in dialysis care(40). A study in the Philippines identified several significant barriers in dialysis care, including long wait times and overcrowding, which limited personalized attention and led to suboptimal care. Financial and geographic constraints also restricted access to quality care, while poor communication between healthcare providers and patients caused confusion and worsened treatment outcomes(41). Similarly, a study in Pakistan found that many dialysis patients experienced frustration and dissatisfaction with their treatment. They often lacked understanding of the dialysis process, highlighting a significant gap in education. Patients also expressed mistrust towards their doctors and reported poor communication, which left them feeling confused and unsupported in their care. These issues led to lower satisfaction and reduced confidence in the healthcare system(42). A study also supports that the healthcare system puts a strain on adults, making it harder for them to live their lives while undergoing hemodialysis. This burden affects their mental and physical well-being.

Financial constraint

A study in Addis Ababa found that the mean annual cost of hemodialysis treatment was 121,089.27ETB (\$4466.59). The direct and indirect costs covered 77.0% and 23.0% of the total costs, respectively. Most of the cost, about 72.9%, came from direct medical expenses. Age, wealth, duration of stay in hospital and other comorbidities were factors associated with the cost

of hemodialysis treatment(43). Another similar study also found that the average cost of hemodialysis in selected hospitals was \$7,739.17, with a variation of \$2,833.51. Most of the cost, about 72.9%, came from direct medical expenses. The type of hospital (private or public) and the length of time on hemodialysis were factors that increased the overall cost of treatment(12).

Similarly, a study in Jimma highlighted that chronic kidney disease patients often face financial difficulties, which make it hard for them to access necessary treatment. Many rely on the support of others to manage their condition(44).

In Uganda, a study showed that paying for medical bills was a major concern for many families. Financial support often came from children, parents, relatives, or sometimes through sponsorship. This financial burden was one of the main challenges mentioned by participants(36).

The above studies outlining the different factors associated with chronic kidney disease and hemodialysis treatment show that the disease and its treatment affects patients in more ways than one. The burdens imposed on these patients cannot just be described using numbers it needs to be understood from the view point of the patients. The factors outlined above need to be studied along with the effects they have on the patients, and they need to be well understood. And no better way to study and understand the effects than from the experiences of those who lived through them.

Impact of hemodialysis on quality of life

Quality of life is an individual's perception of their position in life in the context of their culture, value system, and relationship to life goals, expectations, standards, and other related matters. Quality of life is an increasingly important factor in the assessment of the management of chronic kidney disease patients undergoing hemodialysis(45).

A study including 124 chronic kidney disease patients undergoing hemodialysis, showed that most patients in the study reported good quality of life (84; 67.7%), and only 40 (32.3%) reported poor quality of life(46).

Another study by Sathvik BS, et al, on the assessment of quality of life (QOL) in hemodialysis patients showed QOL of hemodialysis patients was found to be significantly ($P < 0.05$) impaired in comparison to the QOL of healthy individuals selected from the general population, particularly

with respect to the physical, psychological, and social relationship domains, but not in the environmental domain(47).

It's not surprising that a chronic disease such as chronic kidney disease and a lifelong treatment that imposes restrictions on its patients, affects the lives of patients and their quality of life. In the above-mentioned literatures, there are great deal of patients that report that quality of life has become poor as a result of going through hemodialysis. This study will provide essential data to improve the overall wellbeing of young adult patients undergoing hemodialysis.

Coping mechanisms of young adult patients undergoing hemodialysis

Undergoing hemodialysis is a very stressful process. Patients are often seen using different coping mechanisms to relieve themselves of the emotional, social, financial and physical challenges they face. Most patients use emotional regulation as a coping mechanism as compared to other coping strategies such as problem solving. Emotional regulation involves finding new attitudes and beliefs, positive reappraisal and increased level of confrontation(48).

A study in Ethiopia found that patients use coping mechanisms such as seeking help from family and friends, reducing frequency of hemodialysis sessions, and cutting back on prescribed medications(12). A study conducted in Iran found that patients preferred emotion focused coping mechanisms compared to problem focused coping mechanisms. The study found a strong association between emotion focused dimensions and coping. Emotion focused dimensions such as finding new attitudes that have a positive outlook about hemodialysis and life in general and receiving positive appraisals were found to be significantly associated with coping(49).

A study conducted in Taiwan among young adult hemodialysis patients aged 20-40 years of age, found three common stressors among them. Fluid restriction, food limitation and fatigue. These groups faced these stressors and others much more than other groups. The groups were reported to use finding meaning in the situation and trying out different solutions for the restrictions as a way of coping mechanism. In this study the participants were found to have favored more the problem focused coping mechanism.(50). The findings of the above studies can serve as evidence that patients use different coping mechanisms to cope up with undergoing the hemodialysis treatment. Focus needs to be given to these different coping mechanisms as they may serve useful for patients.

A study in Iran also found that patients used social support as a coping mechanism. The study highlighted that there was a significant association between death anxiety and resilience in patients undergoing hemodialysis. However, social support was found to be a major mediating factor between the two helping patients in resilience(51).

Objectives

General objectives

- ✓ To explore the lived experiences of young adult patients with chronic kidney disease who are on hemodialysis treatment.

Specific objectives

The study assessed the following specific objectives

- ✓ Explore the different challenges faced by adults undergoing hemodialysis treatment,
- ✓ Explore the coping mechanisms of young adult patients undergoing hemodialysis treatment,
- ✓ Explore patients' perception towards the hemodialysis process

Materials and methods

Study setting and period

This study was conducted in selected health facilities of Addis Ababa (AA), the capital city of Ethiopia.

Beginning in the 1970's Ethiopia has been implementing the primary health care system throughout the country. Since 1993 the primary health care system has been the core of the country's health care scheme. Currently the country's health care system is a four tier which comprises of primary health care units (PHCUs), district hospitals, general hospitals and specialized hospitals. (52).

Most of the major specialized hospitals are located in this city. The city's health care system is divided into 10 administrative zones with five public and 25 private hospitals (51). In recent times, with the growing number of chronic kidney disease patients, dialysis centers across Addis Ababa have also been growing.

In a survey conducted on September 2021, there were 35 hemodialysis units in Ethiopia. Eleven units were government owned hospitals while the remaining units were private for-profit units. The majority of the dialysis centers and patients are concentrated in the capital city of Addis Ababa, where 23 of the 35 units (66%) and 77% of the patients receiving dialysis are located; however, the city accounts for only about 4% of the total population of the country(17).

Out of the 23-dialysis units located within the capital city, 19 of them are private owned dialysis centers.

The study was conducted in three purposively selected private owned dialysis centers namely Addis Hiwot general hospital, Lancet General hospital and Yanet General Hospital from January 2025 to May 2025. Private facilities were selected for the study because of availability of maintenance hemodialysis as compared to governmental facilities, which currently are only providing services for only acute kidney injury (AKI) patients. The three facilities were selected because of the relatively large number of patients on hemodialysis treatment, and availability of trained sub-specialized nephrologist who regularly follow-up the patients.

Study approach

A phenomenological qualitative approach proposed by [Edmund Husserl, 1913](#), referred to as descriptive phenomenological study was employed to gain an in-depth understanding of the lived experiences of dialysis patients. Descriptive phenomenological study is a study that remains closely aligned to the original experiences and aims to distinguish, understand, and make clear the essential feature of a defined phenomenon from the viewpoint of the persons directly involved (54). This approach aims to describe the essential meanings and structures of the phenomena without imposing any preconceptions or interpretations. The data analysis process involves four steps: bracketing, horizontalization, clustering, and textualization. The consolidated criteria for reporting qualitative research (COREQ) checklist was also used to promote the rigor, credibility and comprehensiveness of the research (55).

Population

All CKD patients visiting dialysis centers in Addis Ababa were considered for the study. The study participants included purposefully selected dialysis patients who have been on dialysis for at least six months, are willing to share their personal experiences during data collection and are aged between 18 and 40.

Selected patients visiting dialysis centers at Addis Ababa general hospital, Lincet General hospital and Yekatit general hospital fulfilling the inclusion criteria were then included in the study.

Study participants

Number of participants used in a previous study resembling this study was found to be 12 to 14 participants (34). Selection of participants was determined upon information redundancy and saturation. Accordingly number of participants was added or reduced.

Purposive sampling was used for this study approach. Participants who were eligible and voluntary for this study were purposefully chosen from the pool of dialysis patients at each selected dialysis centers.

Recruitment of participants

A purposive sampling method was used to select participants for this qualitative study. This approach involved identifying and choosing individuals who have direct experience with the

dialysis process and can provide detailed insights into their lived experiences. The sample size, categorized into healthcare facilities, is outlined below (Table 2).

Recruitment was carefully planned to capture a diverse range of patient perspectives that reflect the study objectives. Efforts were made to include patients with varying treatment histories, ages, and backgrounds to ensure a comprehensive understanding of their experiences. Key hospital staff, such as dialysis unit coordinators and nursing supervisors, were consulted to help identify suitable participants. Patients were selected from the three chosen private facilities based on the number of patients receiving the services. Four patients were selected from Addis Hiowt general hospital, seven patients from Lancet general hospital and three patients from Yanet general hospital. Lancet general hospital provided hemodialysis treatment for majority of the patients hence, larger proportion of selected participants were allocated to it. Subsequently, Addis Hiowt general hospital had the second highest number of patients receiving hemodialysis treatment and hence the allocation of the second highest number. A total of fourteen participants were chosen. However, it needs to be noted that this number was dependent upon information saturation.

Table 1: number of patients selected centers provide dialysis for (recruitment of participants)

Selected health facilities	Number of total patients	Number of sessions per day
Addis Hiowt general hospital	38	3
Lancet general hospital	80	5
Yanet general hospital	30	4

Table 2: sampling of targeted participants

Selected health facilities	Key hospital staff consulted for patient identification	Expected number of participants to be selected from each facilities
Addis Hiowt general hospital	Head dialysis nurse	4 plus one health care provider
Lancet general hospital	Head dialysis nurse	7 plus one health care provider
Yanet general hospital	Head dialysis nurse	3 plus one health care provider
TOTAL		17

Additionally, healthcare workers providing dialysis were interviewed to help in triangulating results. The number of healthcare workers to be interviewed was dependent on information saturation and they were also purposively selected.

Data collection methods

The data collection method for this study primarily involved an in-depth, semi-structured interview with dialysis patients.

Interviews were conducted with eligible participants in a comfortable, private setting within the healthcare facility or another location chosen by participants to ensure confidentiality and ease. Each interview lasted approximately 40–50 minutes, depending on the participant's comfort and willingness to share.

A semi-structured interview guide was used to cover key topics while allowing flexibility for participants to discuss additional relevant experiences. With participants' consent, each interview was audio-recorded to capture their words accurately. Throughout the interview process, the interviewer also took field notes, capturing non-verbal cues, emotional tones, and immediate reflections. These notes supplemented the audio-recorded data and contributed to a fuller understanding of participants' experiences.

Data processing and analysis

After each interview session, the recorded information on an audio recorder was transcribed using a clean verbatim transcription approach by the interviewer, capturing the exact words and meaning of the speaker while omitting unnecessary filler words and non-verbal sounds for better clarity. The Amharic transcriptions were then translated into English and aligned with the interviewer's field notes. The transcribed and translated format was presented to each participant for their approval and consistency of the transcription and translation. Open Code 4.03 software was used to store and manage these interview transcripts. Subsequently, a preliminary analysis followed to assess information saturation and identify emerging themes. Data collection ceased when the saturation point was reached, and no new codes were expected. Thematic analysis was applied to analyze the transcribed interviews. Efforts were made to uphold the qualitative study's credibility, dependability, transferability, and conformability which is outlined in the next section.

Table 3: table of the description of the coding tree

Major themes	Sub-themes	Representative codes
Hemodialysis experience	Physical and emotional experience	<i>"I usually describe dialysis as slow depletion of the body and spirit, just like a steady stream"</i>

		<i>would do to a pile of soil."</i> Physical and emotional depletion
	Financial experience	<i>"I've sold everything—my house, my land, even my wife's jewelry. And still, I wonder if it's enough."</i> economic depletion
	Availability, accessibility and efficiency of healthcare	<i>"Sometimes, the machines fail. Sometimes, there's no doctor when you need one,"</i> lack of facility and care
	Experiences associated with caregivers	<i>"I believe she always worries thinking what if he collapses? What if we run out of money?"</i> worrying for caregivers
Treatment experience and health status of hemodialysis patients	Perceived effectiveness and gratitude for treatment	<i>"The treatment I am receiving is good, and having access to this kind of service is a blessing."</i> Gratitude
	High prevalence of comorbid conditions	<i>"There are lots of treatments I am receiving, because I have different diseases other than the kidney disease. I have heart disease, goiter, blood pressure in addition to the renal disease. I am taking medications for all these diseases I am diagnosed with."</i> comorbidities
	Underlying causes and secondary diagnoses	<i>"The primary condition leading to renal failure in most patients are diabetes and hypertension."</i> Causes of renal failure
	Life style modifications	<i>"...I limit my water intake, as increased water consumption can lead to difficulty breathing and other complications."</i> restrictions
Treatment adherence		
Diet and nutrition		

Interaction with healthcare workers		
Challenges and coping mechanisms	Physical and emotional challenges	<i>"I feel like I have no energy left in me after I finish my dialysis session."</i> Physical challenges
	Economic challenges	<i>"The economic burden gets you so confused and uncomfortable".</i> Financial burden
	Social challenges	<i>"I used to be a kindergarten teacher. Now I'm just 'the sick one,'" stigma</i>
	Coping mechanisms	<i>"I would tell them that dialysis is a demanding process that requires a lot of adjustments in lifestyle. It can be physically exhausting and emotionally draining, but it is manageable with the right support and mindset"</i> peer support

Trustworthiness (Rigor)

The four basic criteria to maintain the rigor of a qualitative study were upheld, and the findings focused on the credibility, dependability, transferability, and confirmability of the study.

For credibility, the investigator managed to create rapport with participants through friendly, open conversations, using good interview techniques. The investigator was able to create a friendly environment. For dependability, the investigator verified the accuracy of transcripts through audio recordings and took detailed notes, using a code-recode strategy. To ensure transferability, the study provided detailed contextual information, and participants were purposively selected, with findings presented clearly to allow replication. For confirmability, the investigator reduced personal bias by reflecting on expectations and experiences while ensuring findings are participants' words and are not manipulated, supported by triangulation of data from multiple sources.

Reflexivity

Reflectivity is crucial in qualitative research, especially when the researcher is also facing similar challenges as the participants, as it allows for a more thoughtful and transparent exploration of how personal experiences may shape the data collection, interpretation and analysis.

I have been battling with CKD and hemodialysis for ten years now. This personal experience with CKD and hemodialysis provides me with a deep sense of empathy and insight into the physical, emotional and social challenges adults face while undergoing the treatment. It also allows me to connect with participants and gain trust and openness. This in turn will create a more comfortable environment for participants to freely share their stories. However, it should be noted that it also raises the potential for biases, as I may project my own experience or assumption on their narratives. Hence, why I engaged in self-reflection throughout the research process. I took steps such as, considering areas where my personal experience and assumption would influence my approach to data collection and analysis. I made efforts to ensure the voices of the participants remained central to the findings of the study, rather than allowing for my personal experiences to overshadow them. I also extended efforts towards creating a balanced approach regarding interactions with participants.

Efforts were made to navigate the complexities of conducting research on a subject that is personally as well as professionally important, while maintaining the integrity and objectivity necessary for high-quality qualitative research.

Operational definition

- ✓ **Chronic kidney disease patient:** a patient with abnormalities of kidney structure or function, present for a minimum of 3 months, with implications for health.
- ✓ **Young adult :** In this research work, young adult refers to individuals who are in the stage of life between adolescence and full adulthood, usually aged between **18 and 40**. Classification is based on Erikson's stages of human development(56).

Ethical considerations

The proposal for this thesis was submitted to obtain clearance from the Ethical Review Committee of Addis Ababa University. Ethical approval for the study was obtained from the Addis Ababa

Regional Health Bureau. A letter of support was written to the selected hospitals from AAU's School of Public Health to inform them about the study.

The data collectors explained the objective of the study and all necessary information to the study participants. Participants were informed that the information they provide was to be accessed only by the principal investigator, and verbal informed consent was obtained from them. Data was kept confidential and used solely for research purposes. In addition, participants were also insured that audio recordings of the interview were to be kept private and accessed only by the principal investigator. In respecting their rights, participants were entitled to ask questions, were not pressured to participate, and had the option to withdraw at any point during the interview. Participants were also informed that no direct incentives will be provided, and they will be asked to allot 40–50 minutes of their time for the in-depth interview (IDI).

Dissemination of the results

The primary aim of this thesis was to fulfill partial requirements for the Master of Public Health in General Public Health specialization. Consequently, the study results will be submitted to the Department of General Public Health, School of Public Health, at AAU. Additionally, copies of the findings will be shared with the participating hospitals and relevant organizations. Furthermore, the findings will be disseminated through presentations at professional, local, national, and international conferences, and efforts will be made to publish the results in peer-reviewed journals, both at the national and international levels.

Results

Six major themes were generated from the data including 1) hemodialysis experience 2) treatment experience and health status of hemodialysis patients 3) treatment adherence 4) diet and nutrition 5) interaction with healthcare workers and 6) coping mechanisms. Additionally, inputs from healthcare workers have also been included as seventh major theme, triangulating the results.

Socio-demographic characteristics

In this study, key informant interviews were conducted with patients diagnosed with chronic kidney disease who are undergoing hemodialysis at three privately owned dialysis centers in Addis Ababa. A total of 17 participants participated in the interviews, including 10 female and 7 male participants. The frequency of dialysis sessions varied among the patients, with some undergoing the procedure once, others twice, and few three times a week, depending on their financial capacity.

Table 4: Socio-demographic characteristics of participants

SEX	
Male	7
Female	10
Age	
<28	7
>28	10
Marital status	
Single	6
Married	6
Divorced	3
Widowed	2
Employment Status	
Employed	5
Unemployed	12
Length on Hemodialysis	
6-23 months	4
24-47 months	7
>48 months	3

Hemodialysis experience

Physical and emotional experience

The findings from this study indicated that living with dialysis had significant physical, emotional, and economic impacts. Most of them reported that they have lost weight, had poor appetite, and also lost interest to engage with their daily life. The treatment's side effects such as nausea, vomiting, and swelling add to the existing struggle of coping up. On top of that, the fact that they had to rely on a machine for survival posed significant challenge for individuals undergoing hemodialysis, as they face the fact that this is now part of their daily lives resulting in feelings of anxiety and depression. This dependency usually contributes to emotional and physical hardships, as patients grapple with a restricted lifestyle alongside the physical toll of regular treatment. One patient aged 38 stated the situation as follows:

"I usually say that dialysis depletes the body and spirit as a water would do to soil."

Following each session is an insurmountable amount of fatigue which makes tasks such as going to taxi stations to go back home hard. Some patients prefer staying in healthcare facilities rather than returning home, not just for medical support but because hospitals offer a temporary escape from the crushing responsibilities and anxieties of their daily lives. One of the study participants aged 34 stated the situation as follows:

"To be honest, I would feel somewhat more at comfort when I stay at the health facility than home. When I stay at the health facility the health professionals and the services are there and I feel safe and hope of getting well soon. However, when you be at home there are a lot of stuff to be done. You think about your health condition, your being coming too weak to do something, your family condition, your kids' life, the economic burden gets your so confused and uncomfortable".

Financial experience

The financial burden is another critical issue, as hemodialysis is a costly procedure especially in countries such as Ethiopia where resources are scarce and there are no subsidiaries to support patients. This expense often forces patients and their families to make significant sacrifices, adding to the stress.

A 35-year-old patient's voice trembled as he spoke with grievance,

"I've sold everything—my house, my land, even my wife's jewelry. And that is still not enough"

It's not just the cost of dialysis that is financially disabling but also associated costs of medications for comorbidities, transportation and laboratory fees as well. A 37 years old patient with many comorbidities described with frustration his situation as follows:

"I don't have other alternatives to not undergo dialysis and also take these medications, unless I undergo dialysis and take these medications the condition of my health will worsen. Therefore, unless I encounter shortage of money or lack of medications in the market, I will undergo dialysis and take the medications regularly as per the prescription "

This is one of the major reasons patients are seen skipping sessions, reducing frequency of dialysis and not taking medication on time risking their health and life in the process. This is the sad reality patients on dialysis face as the treatment that is supposed to make their health condition better is also what is causing them to lose everything.

Availability, accessibility and efficiency of healthcare

Setting the financial constraints aside, poor access to facilities and inadequacy makes dialysis harder on patients. Many lack access to specialized care, vascular access treatments, or even basic medical support, causing feelings vulnerability and neglect among patients. Healthcare accessibility remains a persistent obstacle. Patients may encounter complications such as infections during dialysis procedures and vascular access failure and care for repair of the vascular access or specialized treatments for the different cases is often inadequate. This lack of resources adds to the already existing challenges faced by patients.

"Sometimes, the machines fail. Sometimes, there's no doctor when you need one," a 22 years old patient muttered with a feeling of despair.

Experiences associated with caregivers

overall quality of life for both patients and their caregivers is also severely affected. Patients often struggle with physical exhaustion and emotional distress that comes along with regular dialysis. Similarly, caregivers, who play a vital role in providing support, also face significant emotional and financial pressures, which is witnessed resulting in compromised quality of life for them as well.

One patient aged 32 describes with worry the feeling he thinks his wife has

"I always think that she always worries about me collapsing? or about us running out of money?"

These interconnected challenges highlight the multifaceted difficulties associated with hemodialysis and underscore the need for comprehensive support systems and improvements in healthcare infrastructure.

Treatment Experience and Health Status of Hemodialysis Patients

Perceived Effectiveness and Gratitude for Treatment

The respondents spoke of their gratitude for the availability of the dialysis treatment, the little amount there is. Many of the participants acknowledged that availability and accessibility, no matter how limited it is, to such clinical care significantly improved their quality of life.

One 27 years old patient said that:

"The treatment I am receiving is good, and having access to this kind of service is a blessing." The use of such a word as *"blessing"* signifies that the availability and accessibility of dialysis to patients was more than just a mere treatment but also gave patients hope for tomorrow.

High prevalence of comorbid conditions

Majority of the patients were found to have comorbid conditions such hypertension, heart disease, diabetes, anemia, joint pain, and gastritis.

A 37 years old participant said that:

"There are lots of treatments I am receiving, because I have different diseases other than the kidney disease. I have heart disease, goiter, blood pressure in addition to the renal disease. I am taking medications for all these diseases I am diagnosed with."

The presence of these comorbidities necessitates patients take additional treatment regimens on top of the already exhausting dialysis treatment. In order for patients to manage their health condition they are forced to adhere to strict medical prescriptions and attendance of their dialysis sessions so that they can sustain their current health condition.

Underlying causes and secondary diagnoses

According to this study, renal failure is often attributed to diabetes and hypertension.

A 32 years old patient said that:

"The primary conditions leading to renal failure in most patients are diabetes and hypertension."

Another 40 years old male who do have regular dialysis at one of the dialysis centers said that:

"I am receiving hemodialysis treatment for my kidney failure. The process takes about four hours each session. In addition to hemodialysis, I manage my diabetes with insulin and other medications prescribed by my doctor."

Most of the patients reported that they developed anemia after having started dialysis. Following the anemia were symptoms such as fatigue, difficulty concentrating, difficulty breathing and pale skin.

Lifestyle modifications

Patients reported adhering to strict lifestyle changes to manage their health. Key modifications included limiting water intake to avoid complications like difficulty breathing, oedema and refraining from strenuous activities. Despite these efforts, many continued to experience persistent symptoms such as physical weakness, fatigue, and electrolyte imbalances.

A 27 years old patient said that

"...I limit my water intake, as increased water consumption can lead to difficulty breathing and other complications."

Although patients undergo these and other lifestyle changes discomfort still remains in the patients' life.

Treatment adherence

Medical intervention and seeking for medical care are not the only requirements of chronic kidney disease patients, strict adherence to medication, treatment, checkup and lifestyle is also necessary. These patients undergo dialysis and on top of that they need to manage the comorbidities. This requires dedication and discipline unlike any other. That is why patients are seen following strict dialysis, medications and dietary adjustments.

As per the respondents' report, almost all patients do have an insight and awareness about the benefits of each and every treatment and also the consequence of not adhering to them, with all patients adhering to treatment unless unforeseen circumstances happen.

One of the respondents aged 25 said that:

"Adhering to the treatment regimen is essential for my health, but it requires a lot of discipline and support from my family. There are times when I feel overwhelmed, but I remind myself of the importance of staying healthy for my loved ones".

Majority of the participants use medications primarily to address high blood pressure and diabetes. However, occasional shortages of essential medicines in the market disrupt adherence for some patients. Adhering to the treatment plan helps patients feel more in control of their condition and health outcomes. Patients prioritize to adhere strictly to the prescribed treatment regimen and medications. Most patients do follow their treatment plans as prescribed, unless there is an issue with the availability of medications in the market, which is a common challenge. According to the respondents' response, they become confident and reassured when they adhere to the treatment regimen as recommended by their physician. This confidence comes from knowing that taking steps to manage their health effectively will reduce the risks associated with their condition. Following the prescribed treatment plan also gives to patients a sense of control and stability in their life, despite the challenges that come with their medical condition.

"I strictly adhere to the prescribed treatment regimen, including taking medications to control blood pressure". Responded one female 26 years old patient.

Another respondent aged 26 reported that:

"I make it a priority to adhere strictly to the prescribed treatment regimen and medications. Most patients like myself are very diligent about following their treatment plans, unless there is an issue with the availability of medications in the market, which can occasionally occur. I feel confident and reassured when I adhere to the treatment regimen as recommended by my physician. This confidence comes from knowing that I am taking proactive steps to manage my health effectively and reduce the risks associated with my condition. Following the prescribed treatment plan also gives me a sense of control and stability in my life, despite the challenges that come with my medical condition".

Diet and nutrition

Patients undergoing dialysis have specific dietary restrictions to ensure they maintain their health and avoid complications. Certain foods are restricted for these patients. For instance, it is advised to avoid consuming raw meat or unpasteurized milk due to potential health risks. Additionally, limiting the intake of high-protein foods, sugary foods and beverages, alcohol, and high-sodium items is strongly recommended, as these can negatively affect overall health and put pressure on the kidneys. Whenever possible, patients have to check for the content of sodium, potassium, and phosphorus when consuming canned goods. This is because these patients are more susceptible to infections such as diarrhea, typhoid, and common colds, because of their suppressed immune system. It is crucial to avoid high-potassium and high-phosphorus foods, as kidneys in patients with renal failure struggle to balance these minerals, which can lead to serious health issues. Patients are also advised/restricted to limit their intake of carbonated drinks and sodas.

“As a dialysis patient, I have specific dietary restrictions to maintain my health and avoid complications. For example, I cannot consume raw meat or unpasteurized milk because my immune system is more vulnerable to infections. I also avoid undercooked foods, certain juices, and large quantities of water” reports one of the female respondents aged 35.

Carbonated drinks and sodas usually contain high levels of phosphorus and sodium, which are harmful to patients with renal failure. It is also important for patients to monitor their fluid intake carefully. Excessive fluid can lead to swelling, difficulty in breathing, high blood pressure, and puts the heart at risk. Drinking the right amount as prescribed by their healthcare provider is essential. It's understandable that sticking to these restrictions can be challenging for patients. However, it is these restrictions that keep patients healthy and prevent them from developing complications. Many patients feel more confident and secure knowing that they are following a treatment regimen that helps manage their condition effectively.

One of the male participants aged 37 reported that

“I avoid high-potassium and high-phosphorus foods, I follow the dietary and nutrition guidelines provided by health professionals strictly”.

Another female study participant aged 32 said that:

"...The dietary restrictions are challenging, but I understand they are necessary for my health. I try to make healthy food choices and plan my meals to ensure I am getting the right nutrients without exceeding my dietary limits".

Interaction with healthcare workers

Most participants have reported about interaction with healthcare workers as being excellent. Participants have created a kind of family-like relationship with healthcare providers. It is because health care providers truly empathize with patients' pain and understand challenges they face. The conversations often extend beyond medical issues to include discussions about family, financial struggles, children, and other social matters. Even when patients are not at the health facility, they stay in touch through phone calls and greetings. Healthcare worker's concern for patients' well-being goes beyond the clinical environment, and they are dedicated to providing the best possible care and support every day, making participants feel valued and cared for. As data generated from respondents revealed; the level of communication was actually beyond the patient's expectation. One male respondent said that,

"We did not really expect such kind of familyhood at a health facility."

What most of the study participants liked was the true value, the deep sense of trust and connection of healthcare providers. This close relationship allows healthcare workers to offer patients more personalized and compassionate care. However, during difficult health situations, the emotional attachment can be challenging. When the pain becomes unbearable and situations become extremely difficult, patients' behavior sometimes changes, and patients may become noisier and more irritable.

Working as a healthcare provider is undoubtedly challenging. When asked what they would do if assigned to a treatment center as health professionals, the key informants emphasized the importance of empathetic and patient-centered communication. They stated that their primary goal would be to create a comfortable environment where patients feel at ease discussing their concerns and experiences. They highlighted the significance of providing clear and accurate information about treatment plans and encouraging patients to ask questions. Additionally, they expressed a commitment to involving patients in decision-making processes to ensure they feel supported and well-informed throughout their care journey.

"I appreciate their care, but sometimes I wish they had more time to address my concerns and provide more personalized support. If I were a health worker, I would ensure to spend more time listening to patients and addressing their individual needs" responded one 24 years old patient.

Furthermore, Healthcare providers have also built a familial bond with patients, going beyond clinical care to engage in personal and emotional support. Communication exceeds expectations, creating trust and reassurance. However, the emotional attachment can pose challenges during difficult health situations, underscoring the need for healthcare workers to balance empathy with professional boundaries. Empathetic communication fosters trust and improves adherence. However, emotional challenges faced by healthcare providers emphasize the need for resilience training and professional development.

Challenges and coping mechanisms

The challenges, most of patient who undergo hemodialysis faces include: physical exhaustion, lack of awareness about kidney health, economic burdens, lack of robust psychological support, lack of peer support or inadequate Social Support, blood sugar levels may drop, blood pressure might increase, feelings of hopelessness, having different comorbid disease, lack of adequate facility access, decreased Urine Output, Painful Urination or discoloration, difficulty in Urine flow, dietary restrictions, mental health and psychosocial related problems, and societal stigma, fatigue, dietary restrictions, and frequent medical appointments.

Physical and emotional challenges

Dialysis affects the body and mind of patients. Patients are fatigued after each session, a fatigue that can only be explained by them and no one else. They also have to face comorbidities. The psychological effect of having to navigate a chronic illness that requires one to live off of a machine is unimaginable. The physical symptoms these patients face is debilitating, sudden drop in blood pressure during dialysis, low blood sugar level, painful urination if there is any. The emotional symptoms are not to be masked by the physical symptoms either. Depression and anxiety are common, exacerbated by the knowledge that this is not a temporary battle but a lifelong war.

One female participant reported

"I feel like I have no energy left in me after I finish my dialysis session."

Another male participant said

“Some days, I look at the machine and think, 'is this how I will be living the rest of my life? This is not fair.’”

Economic challenges

One of the respondents aged 38 said that:

“The economic burden gets you so confused and uncomfortable”.

The financial burden caused as a result of dialysis almost always leaves patients and their families in ruins, causing them to lose everything. Especially in countries like Ethiopia, where there are no financial schemes in place to help patients cope with the debilitating financial problems. The financial burden is not to solely be attributed to dialysis, but also the cost of medications towards comorbidities especially hypertension, diabetes and anemia.

Social challenges

Dialysis patients often face societal misunderstandings and loneliness. The treatment schedule disrupts social interactions. The strict dialysis schedule usually cuts societal ties of patients to community and work.

“I used to have a job, but I can’t work now because I have to be here three times a week.” speaks a respondent with uneasiness in her sound.

It also creates adrift between families, as some patients opt to hide their pain to avoid *“being a downer.”* The loneliness is a silent side effect no prescription can fix.

Coping mechanisms

The respondents highlighted several key coping mechanisms, diligently following the treatment plan, empathizing with patients' pain, receiving some level of support from the government and NGOs, engaging in spiritual practices, benefiting from the care and encouragement of healthcare professionals, and finding strength through shared experiences with others, regular check-ups and a healthy lifestyle. Additionally, ensuring not to overhydrate, focusing on maintaining a balanced diet by incorporating fruits, vegetables, whole grains, and lean proteins, minimizing intake of salt, processed foods, and excessive sugar, as these can burden the kidneys, taking care with foods that are rich in potassium or phosphorus, keeping blood pressure and blood sugar levels in check,

staying active with regular exercise to help manage blood pressure and maintain a healthy weight, refraining from smoking, limiting alcohol consumption, sustaining a healthy body weight, and prioritizing getting sufficient rest.

As per the response of a 40 years old participant:

“When a new patient comes to the facility; existing patients reassure new patients by sharing their experiences. For example, they will tell to these new patients about their own personal experiences and how they got through it or the experiences of other patients who have been in the ICU but are now doing well and successfully managing their businesses alongside their dialysis treatment.”

They emphasize to the new patients that they are not alone in this journey rather there are many others who are facing the same challenges. And again, respondents introduce confidence in them by expressing their belief that they too will be able to cope with the situation.

“Over time, patients often tell us that the initial advice and reassurance we provided were instrumental in helping them cope with the challenges they faced.” Expresses one respondent with a smile on her face.

Respondents also inform the new patients about the physical and emotional challenges they might encounter, such as fatigue, dietary restrictions, and the need for frequent medical appointments. And they encourage them to maintain a positive outlook, follow their treatment plans diligently, and seek support from healthcare professionals, family, and friends. By sharing real-life success stories and offering continuous support, existing patients help new patients build resilience and adapt to their new reality.

“I would tell them that dialysis is a demanding process that requires a lot of adjustments in lifestyle. It can be physically exhausting and emotionally draining, but it is manageable with the right support and mindset” said one 32 years old female patient.

Perception of health care providers

Although there are different types of dialysis the focus of this study was on in-center hemodialysis. Patients had to go to the hospital or dialysis center constantly as dialysis is a procedure that requires

patients to be attached to a machine that will function for them as their kidneys would. This procedure is recommended to be done at least three times a week for four hours. This implies that patients are in constant contact with their health care providers. Making the perceptions of health care providers significant.

Health care providers view on patients' challenges

Health care providers pointed out that there are different types of challenges patients face in the course of undergoing dialysis. They mentioned challenges such as financial, physical, psychological, social and emotional challenges.

One of the nurses at Yanet general hospital said

“One of the problems that dialysis patients face is the economic problem. That is, they are paying a lot of money for dialysis for a long time. The problem that More Challenge is facing and what makes the job very difficult is the economic problem.”

Another respondent also pointed out

“There are health problems in the patients, sometimes blood pressure drops, blood sugar drops, and different things.”

One of the respondents retaliated that the pile up of different challenges and the psychological stress it causes to patients really cause an emotional toll on patients. She spoke of this by saying

“What is seen is that dialysis patients are emotionally affected, because first, there is an impact on them that their health is being affected, second, there is an economic impact, third, there is a family problem, and these are all these things.”

Another respondent also pointed this out saying

“They get emotionally hurt on the simple things, they get stressed out and disturbed over silly things...”

Challenges in providing dialysis

There are different challenges health care providers themselves face as they are engaged in providing dialysis treatment for their patients. One respondent claimed that there exists lack of awareness amongst patients about their treatment and the outcomes it brings along with it, she said

“First, there is no awareness on the part of the patient. Most of them do not have awareness. Dialysis patients do not have much knowledge about dialysis...”

Another dialysis nurse mentioned that the equipment needed for dialysis are very expensive to procure causing delays in providing dialysis or increasing the cost of dialysis on patients, she explained as

“Dialysis treatment is a capacity-challenging process, so there are various challenges associated with capacity. There may be a lack of capacity in the current situation. Again, I think it is a bit difficult because the materials are a bit expensive.”

This was strongly supported by another nurse from a different center in which she replied

“The main problem the cost of living and the supply of goods are very expensive. It is also expensive to buy a machine. If there are not enough machines, we will not be able to accept people who want to do dialysis as they want. This is what has put us in trouble.”

Support

Dialysis patients need constant support from whoever they can get it. Since the treatment is a very difficult and hard to carry on by oneself, support for these patients is necessary. Support from any source is welcomed with open arms and support from health care providers is a much needed one. The health care providers say that they start lending a supporting hand from the time a patient enters the dialysis room and that helping hand extends far beyond the dialysis room. One participant, with a bright smile on her face proclaimed

“.... we ask them, first, when the patient comes in, we communicate a lot, asking, "How are you?", "What are you experiencing?", "What are you doing?", "How are things going?", "What do you think? And we try to support them as much as we can by trying to listen to what they have to say.”

The response of one respondent shows the intra-dialysis care and support they provide for their patients,

“...many things happen during dialysis, when these things happen, we approach the patient and explain to them that there is a solution to each problem, just like family, so that they accept us immediately. That's how we ensure that.”

Accessibility and affordability

Health care providers do not believe that dialysis service is accessible and affordable. They believe that the service cost is very expensive and hard on patients, rendering patients unable to receive treatment. One respondent spoke of this with frustration and anger saying

“I don't believe that this service is accessible and affordable. I believe that it is a sector where not much has been done as a country and I really want more work to be done on it and for the government to pay attention to it, and for the wealthy to pay attention to it because there are so many people and yet the service is not being accessed. I mean even in Addis Ababa it is still yet to be accessible let alone the rural areas; it's at the point where you can say the service doesn't exist in rural areas. And I just hope that the relevant authorities pay attention to making this service accessible. And I don't believe that it is accessible and affordable.”

Health care providers also put emphasis on the fact that supplies for dialysis treatment are imported from abroad and that make the service expensive. With one respondent mentioning

“I don't think it's affordable or accessible. Personally, I think it's a little expensive in terms of our lifestyle, and I think it's not accessible. I think it's a little inaccessible because everything comes from abroad in terms of supply and availability.”

Availability of machines were also mentioned as one challenge where accessibility was put into question.

“I can't say it's accessible to everyone because we don't have enough machines. On the other hand, dialysis is very expensive, so we can't say it's affordable.” The respondent speaks of not having enough machines to provide care for patients but could do so if there were more machines.

“If there are not enough machines, we will not be able to accept people who want to do dialysis as they want. This is what has put us in trouble.”

Opinions from patients

Dialysis patients provide different feedbacks to their health care providers. Not only they give feedbacks to the treatments they receive they also will develop their own opinion about their dialysis treatment and their health status. One feedback a health care provider received was

“They tell us that they are happy with us and that they are happy when they come to our center for dialysis...”

However, health care providers reported that most of the opinion patients formulate themselves and give as feedback to them are illogical and unscientific. One respondent says

“But sometimes patients think that dialysis is only done to remove fluid, and that is a trend they are used to, other things they usually say ‘I have gained this much today so I need you to remove this much amount of fluid’ or ‘my blood pressure went down, so I didn’t take my medicine’ or ‘I drank this much fluid, so this is why I am like this.’ These are some of the illogical and unscientific things that I have seen.”

Another respondent spoke of these self-developed opinions as

“For example, when their blood pressure drops or rises, we hear different ideas about the amount of fluid they lose per session, the increase or decrease in their blood sugar, and laboratory results, but we continue to explain it scientifically.”

Another respondent however viewed this self-developed opinion as awareness by the patients about their health status and the dialysis procedure. She states

“Most of them know certain things, such as how much fluid they need, how much fluid they need to take, and what medications they need to take, because they often encounter them, and they learn from their experience.”

Discussion

The findings reveal the complex interplay of medical, emotional, social, and economic factors affecting dialysis patients. Renal failure's systemic impacts, including comorbidities and immunity vulnerabilities, underscore the need for holistic care. Despite effective dialysis, patients face significant adjustments in daily life. The emotional and physical toll of dialysis is profound. The respondent's preference for the health facility highlights the importance of supportive environments in mitigating stress.

"Patients often feel more at ease at the health facility but struggle with loneliness and tension when at home." Adherence to treatment and dietary guidelines is vital for managing chronic kidney disease but poses challenges due to restrictions and occasional medication shortages.

"High-phosphorus foods and excessive fluids are restricted. While challenging, adhering to these guidelines is essential for patient well-being."

Empathetic communication fosters trust and improves adherence. However, emotional challenges faced by healthcare providers emphasize the need for resilience training and professional development.

"Their care makes me feel valued and cared for."

Economic hardships, societal stigma, and physical limitations highlight the need for policy interventions and community support.

"The economic burden gets you so confused and uncomfortable."

Expanding dialysis services, providing financial aid, and increasing awareness about kidney health are critical steps to alleviate burdens on patients.

"Establishing patient associations would allow us to share burdens, including economic challenges."

Another key informant reported that

"I would like to emphasize the importance of a strong support system, both from family and healthcare providers. It makes a significant difference in coping with the challenges of hemodialysis."

Hemodialysis experience

The hemodialysis experience was physically and emotionally exhausting, with frequent sessions (up to three times per week) leaving patients weakened and depressed. The reliance on machines posed significant challenges, contributing to emotional and physical hardships. A study in India emphasizing the results of this study also reported similar findings. A respondent in that study reported

“I feel, as if I am dead, my mind is not there with me, no interest to live... I can no longer feel or enjoy anything.”(57).

A different study conducted in India also showed that patients felt restricted to participate in different activities, restriction in diet, fatigue associated with lack of strength and energy, and decreased ability to perform their jobs(58) which aligns with the findings of this study as well. The consistency of physical and emotional exhaustion across studies and countries shows the gruesome side of dialysis and points out areas where intervention is much needed while caring for dialysis patients.

Financially, the procedure was costly, forcing many patients to make significant sacrifices, such as selling assets, as reported by participants in this study. A study on the economic burden of hemodialysis in Addis Ababa quantified this, reporting an annual mean cost of \$7,739.17, with direct medical costs comprising 72.9%, and noted that 95.3% of patients reported insufficient income to cover costs(12). This aligns with the provided study’s emphasis on financial strain, with patients reducing sessions due to cost. The similarity in financial burden across studies highlights a critical area for intervention, with an alternative explanation for cost variations being the type of facility (private vs. public), as private facilities were found to increase costs significantly.

Healthcare accessibility remained a persistent obstacle, with complications like infections during dialysis and inadequate access to advanced care adding to the already existing challenges. A study in Pakistan supports the findings of this study, which reported patients couldn’t find access to dialysis due to health facility scarcity(59). A study in Nepal also strengthens the finding of this study in which reported was a respondent’s response as

“If we have any health problem, then we need to go to OPD to meet the Doctor. Here in the HD ward, we could not get to meet the doctor....” (60).

Addition of more dialysis centers with available resources and medical personnel should be taken into consideration.

An unexpected detail from this study was patients preferring to stay at health facilities for comfort and security, feeling more confident with professional care compared to the stress of home environments due to family and financial pressures. As can be noted from the response of one of the respondents who said,

“To be honest, I would feel somewhat more at comfort when I stay at the health facility than home... When I stay at health facility the health professionals and the services are there and I feel confident having the service get well soon.”

This preference highlights the importance of supportive healthcare environments, a finding less emphasized in other studies but critical for patient well-being.

Treatment experiences and health status of hemodialysis patients

Patients in this study expressed gratitude for the availability and efficacy of dialysis treatment, despite facing significant comorbidities such as high blood pressure, heart disease, diabetes, and symptoms like fatigue, nausea, and physical weakness. Renal failure was often linked to diabetes and hypertension, with common associated conditions including joint pain, gastritis, cardiovascular diseases, anemia, and increased infection vulnerability due to compromised immune systems. These finding aligns with other studies, such as a study from Jimma, Ethiopia, which reported similar comorbidities and outcomes among hemodialysis patients, clinical characteristics and outcomes of patients on hemodialysis at Jimma medical center(61). The findings of this study also align with a study in Ghana which reported that hypertension was the major underlying cause for patients to end up on dialysis(62).

The consistency in comorbidity profiles across studies suggests a systemic challenge in managing multiple health conditions alongside renal failure, particularly in resource-limited settings. An alternative explanation for any variation could be differences in patient screening or diagnostic capabilities at different centers.

Treatment adherence

Treatment adherence was generally high, with patients following strict regimens of dialysis, medications, and dietary adjustments, aware of the benefits and consequences of non-adherence.

However, occasional shortages of essential medicines disrupted adherence, particularly for managing high blood pressure and diabetes. This finding is consistent with the Bahir Dar study, which reported nonadherence due to cost and service delivery issues like machine breakdowns(63). The Addis Ababa economic burden study also noted patients cutting back on medications as a coping strategy, potentially compromising health(12). The consistency in financial barriers to adherence suggests a need for systemic solutions, with an alternative explanation for medication shortages being regional supply chain disruptions.

Diet and nutrition

Patients faced strict dietary restrictions, advised to avoid raw meat, unpasteurized milk, high-protein, sugary, and high-sodium foods, and to monitor fluid intake carefully. These restrictions were challenging, with patients reporting difficulty adhering due to limited resources and health impacts. This is echoed in the Bahir Dar study, describing dietary restrictions as a “*double burden*” limiting food choices(63).

A cross-sectional study on dietary intake and nutritional status of patients in Sub-Saharan Africa showed that there is a strong association between consumption of high protein, potassium and salt containing foods and health complications among patients undergoing hemodialysis(64), solidifying the fact that these patients are made to strictly adhere to a specific kidney friendly diet, which is also complemented by another study in Malaysia(65).

The consistency across studies underscores the universal nature of this challenge, with an alternative explanation for adherence difficulties being cultural dietary preferences conflicting with medical advice.

Interaction with healthcare workers

Interactions with health workers were overwhelmingly positive, with patients reporting familial relationships and empathetic communication. Participants described their relationships with healthcare providers as “*family-like*,” where communication extended beyond medical concerns to include personal and social issues. This aligns with previous researches indicating empathetic and patient-centered communication enhanced patient satisfaction and led to a better health quality for patients(66,67). However, the study also revealed these close relationships also posed problems especially when patients are facing medical emergencies. During such emergencies emotions of healthcare providers usually cloud their judgment. This finding was supported by a study that

showed healthcare workers must build a boundary between their emotions, emotional involvement, empathy and professional practice so as to maintain effective care(68). An alternative explanation for any variation could be differences in provider training or patient expectations at different centers.

Challenges and coping mechanisms

Patients undergoing dialysis face different kinds of challenges including physical exhaustion, anemia, hypertension, diabetes, lack of awareness about kidney health, economic burdens, lack of psychological support, stigma and dietary restrictions.

Physical exhaustion, anemia, hypertension and diabetes were reported to be the most common symptoms and challenges faced by patients. This finding is in line with a study which underscores fatigue as a debilitating side effect of dialysis(69), a study in Tanzania which found anemia to be very common among dialysis patients(70), a study in America which reported that >80% of patients on maintenance hemodialysis have hypertension problems(71) and another study in the USA which reported >60% patients on maintenance hemodialysis have diabetes(72).

A respondent one study reported

“Is this how I will be living the rest of my life?”(73).

Highlighting the financial burden dialysis places on patients. The financial strain of dialysis treatment, together with costs of managing comorbidities, creates economic hardship, particularly in low-resource settings like Ethiopia, where insurance coverage is limited. A similar study in Ethiopia also supports the findings of this study(12) as well as a systematic review on the cost of dialysis in LMICs(74). The consistency in financial and emotional challenges across studies suggests a systemic issue, with an alternative explanation for coping variations being the availability of community resources.

Coping mechanisms included spiritual practices, support from healthcare providers, and peer encouragement, with respondents reassuring new patients by sharing success stories, such as those who managed businesses alongside dialysis. Participants in this study reported that they help each other out whenever in need, this aligns with a study on peer support in chronic illness management(75). Patients also use advice from healthcare providers on treatment adherence as coping mechanism. They also take advice from other patients to encourage themselves and give

advice to others so as to encourage other patients as well. This shows that social support improves patients' health and their outcome. Which aligns with a study that supports this finding(76).

Perception of health care providers

There was a unique result found in this study. Patients preferred to want to be at the dialysis center more often than to stay at home or not in the dialysis center. The results found from health care providers also support this finding on the patient's side.

A study in Canada states that one participant in that study wished

“It would be nice if they could just, I don't know, listen to me more”(77).

This shows that patients want to be heard and want to talk about what is stressing them out. On this study health care providers claimed that they provide support such as listening to their patients as a support method.

“Many things happen during dialysis, when these things happen, we approach the patient, listen to them and explain to them that there is a solution to each problem, just like family, so that they accept us immediately. That's how we ensure that.”

A study in Tanzania found that Unavailability and high costs related to utilization of hemodialysis services among patients needing dialysis are the challenges for better outcomes(78). This aligns with what the health care providers spoke of about the availability and accessibility of dialysis.

Another study also supports this finding stating that shortage of machines and unavailability of consumables are part of the major challenges health care providers face in providing their services(79).

Health care providers had a perception of what the challenges to patients could be. They stated that patients go through different types of financial, emotional, psychological and social challenges. The fact that dialysis is expensive, patients require constant monitoring, the effects of dialysis have a debilitating effect on patients resulting in psychological and emotional problems, and the social challenges is not to be put into contention. These findings correspond with studies from Africa, sub-Saharan Africa, Tanzania, Poland and Vietnam(78,80–83).

Health care providers also reported that they sometimes receive opinions from patients that they deem illogical and unscientific reporting that some patients don't have enough knowledge about their treatment. Such opinions as patients claiming to have gained much weight because they drank

a lot and wants a certain amount of fluid to be removed for them. Not taking into consideration the different criteria required for removing fluid.

This finding is in line with a study in Pakistan that reported that patients lacked understanding of the dialysis process, highlighting a significant gap in education(42).

Strength and limitation of the study

This study offers valuable insights about the emotional, social, financial and physical experiences of chronic kidney disease patients undergoing dialysis in three private dialysis centers located in Addis Ababa, Ethiopia.

Strength of the study

- **Provides in-depth understanding of patient experiences**

This study focused on the personal lived experiences of patients, thus providing detailed insight into the emotional, social, financial and physical challenges and experiences these patients face.

- **Patient-centered testimonies and identification of hidden challenges**

This study gave patients the chance to speak of their story, challenges, struggles and coping mechanisms. As such it revealed the different challenges and coping mechanisms. It also revealed a unique result.

- **Flexibility in data collection**

As this was a phenomenological study it used methods such as in-depth interviews (IDIs) which followed with probing questions. Leading to a deeper understanding of patients' experience.

- **Foundation for further research and support for healthcare improvement**

Using the findings of this study other qualitative as well as quantitative studies could be performed for further investigations. It can also be used for interventions to improve the quality of life of dialysis patients as well as improve dialysis care in Ethiopia.

Limitation of the study

- **Potential bias during data collection and interpretation**

Interpretation of experiences mainly depends on the researcher, with personal ties to the case as well, which can be biased. Experience of the researcher, personal ties with the study and time restraints are some of the reasons for possible bias.

- **Dependence on patients' ability to recall history and to answer in all honesty**

Different factors can affect the ability of a patient to recall, and narrate during the IDIs. Factors such as memory capacity, length on dialysis, state of mind and presence of depression and anxiety can cause recall bias.

Conclusion

This qualitative study explored the lived experiences of adults aged 18–40 years old with chronic kidney disease undergoing hemodialysis, emphasizing challenges, coping mechanisms, and perceptions of treatment. The findings reveal a complex interplay of physical, emotional, economic, and social struggles, alongside coping mechanisms that help patients navigate their condition. Participants reported severe physical exhaustion, treatment side effects such as nausea, fatigue, hypotension, and emotional distress, including depression and anxiety. The fact that patients had to undergo dialysis for as long as they live, unless otherwise kidney transplantation is provided, led to concerns, with one participant describing dialysis as

"Slow depletion of the body and spirit."

Economic hardships were unavoidable, with many patients facing financial crisis due to treatment costs, medication expenses, and lost income. Socially, dialysis disrupted work, education, and relationships, leading to isolation and stigma. However, even with the existence of the above-mentioned challenges, patients still found ways to cope. Patients gained resilience through faith, social support, and positive healthcare interactions.

However, patients were also not reluctant on mentioning the existence of healthcare inaccessibility, lack of availability and efficiency together with a need for improved psychosocial care.

The study suggested that adults face unique burdens, including career disruption and social alienation, alongside physical symptoms, the need for adaptive strategies centered on peer networks, self-discipline, and external support systems. It also indicated that although patients viewed dialysis a lifeline, they also found it to be a source of emotional distress causing anxiety and depression.

The preference for health facilities over home environments was an unexpected insight, suggesting a need for enhanced outpatient support systems.

Finally, the findings of the study indicate the need for a shift from purely clinical management to a more holistic approach addressing the physical, social, emotional and financial needs, needs to be put in place.

Recommendations

Based on this analysis, the following recommendations are proposed:

1. **Financial Support:** Increase government subsidies or fee waivers for hemodialysis, explore insurance models, and establish dedicated funds for patients.
2. **Healthcare Infrastructure:** Improve dialysis machine reliability, address power supply issues, and expand centers to reduce travel burdens.
3. **Peer Support Programs** – create an environment where patients can share their experiences and use those to create resilience amongst themselves.
4. **Patient Education:** Provide culturally tailored education on diet and medication adherence, and establish peer support groups.
5. **Psychosocial Support:** Integrate psychological counseling into care and train providers in empathetic communication.
6. **Research and Policy:** Conduct longitudinal studies on outcomes and advocate for renal care prioritization in national health policies.
7. **Community Engagement:** Raise awareness about kidney disease prevention and encourage community support through volunteer programs.
8. **Workplace, school and Social Reintegration** – create awareness among employees, school and society so as to understand the patients and create a flexible work environment for patients.

References

1. Stevens PE, Ahmed SB, Carrero JJ, Foster B, Francis A, Hall RK, et al. KDIGO 2024 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney Int.* 2024 Apr;105(4):S117–314.
2. Jager KJ, Kovesdy C, Langham R, Rosenberg M, Jha V, Zoccali C. A single number for advocacy and communication—worldwide more than 850 million individuals have kidney diseases. *Nephrol Dial Transplant.* 2019 Nov 1;34(11):1803–5.
3. Kaze AD, Ilori T, Jaar BG, Echouffo-Tcheugui JB. Burden of chronic kidney disease on the African continent: a systematic review and meta-analysis. *BMC Nephrol.* 2018 Dec;19(1):125.
4. Luyckx VA, Cherney DZI, Bello AK. Preventing CKD in Developed Countries. *Kidney Int Rep.* 2020 Mar;5(3):263–77.
5. Ammirati AL. Chronic Kidney Disease. *Rev Assoc Medica Bras* 1992. 2020 Jan 13;66Suppl 1(Suppl 1):s03–9.
6. Desta BZ, Dadi AF, Derseh BT. Mortality in hemodialysis patients in Ethiopia: a retrospective follow-up study in three centers. *BMC Nephrol.* 2023 Jan 4;24(1):3.
7. Murdeshwar HN, Anjum F. Hemodialysis. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2024 [cited 2024 Jul 9]. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK563296/>
8. Siqueira FBDS, Neves ET, Ribeiro AC, Silveira AD, Paula FMD, Oliveira DCD. EVERYDAY LIFE OF ADOLESCENTS AND YOUNG PEOPLE UNDERGOING HEMODIALYSIS TREATMENT IN THE LIGHT OF AGNES HELLER: A CASE STUDY. *Texto Contexto - Enferm.* 2023;32:e20230043.
9. Viegas ADC, Muniz RM, Schwartz E, Dos Santos BP, Matos MR, Monfrin XM. Expectativas sociais vivenciadas pelo adulto jovem com a doença renal crônica Social expectations experienced by young adults with chronic kidney disease. *Rev Pesqui Cuid É Fundam Online.* 2016 Jul 15;8(3):4850–6.
10. Ofori-Ansah S, Evans M, Baillie L, Moorley C. Young adults with kidney failure lived experiences of kidney replacement therapy decision-making. *J Ren Care.* 2024 Dec;50(4):454–67.

11. Ulasi II, Awobusuyi O, Nayak S, Ramachandran R, Musso CG, Depine SA, et al. Chronic Kidney Disease Burden in Low-Resource Settings: Regional Perspectives. *Semin Nephrol.* 2022 Sep;42(5):151336.
12. Baye TA, Gebeyehu H, Bekele M, Abdelmenan S, Ashengo TA, Mengistu B. The economic burden of hemodialysis and associated factors among patients in private and public health facilities: a cross-sectional study in Addis Ababa, Ethiopia. *Cost Eff Resour Alloc.* 2024 Apr 4;22(1):25.
13. Hill NR, Fatoba ST, Oke JL, Hirst JA, O’Callaghan CA, Lasserson DS, et al. Global Prevalence of Chronic Kidney Disease - A Systematic Review and Meta-Analysis. *PloS One.* 2016;11(7):e0158765.
14. Ali A, Mulatu K, Feleke SF, Wassie GT. Prevalence of chronic kidney disease and associated factors among patients with underlying chronic disease at Dessie Referral Hospital, East Amhara Region, Ethiopia. *Front Epidemiol.* 2023;3:1154522.
15. Sun P, Ming X, Song T, Chen Y, Yang X, Sun Z, et al. Global burden of chronic kidney disease in adolescents and young adults, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *Front Endocrinol.* 2024 Sep 18;15:1389342.
16. Suh MR, Jung HH, Kim SB, Park JS, Yang WS. Effects of regular exercise on anxiety, depression, and quality of life in maintenance hemodialysis patients. *Ren Fail.* 2002 May;24(3):337–45.
17. Mengistu YT, Ejigu AM. Global Dialysis Perspective: Ethiopia. *Kidney360.* 2022 Aug 25;3(8):1431–4.
18. Levey AS, Eckardt KU, Tsukamoto Y, Levin A, Coresh J, Rossert J, et al. Definition and classification of chronic kidney disease: a position statement from Kidney Disease: Improving Global Outcomes (KDIGO). *Kidney Int.* 2005 Jun;67(6):2089–100.
19. Webster AC, Nagler EV, Morton RL, Masson P. Chronic Kidney Disease. *The Lancet.* 2017 Mar;389(10075):1238–52.
20. Vaidya SR, Aeddula NR. Chronic Kidney Disease. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2025 [cited 2025 May 26]. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK535404/>

21. Kovesdy CP. Epidemiology of chronic kidney disease: an update 2022. *Kidney Int Suppl.* 2022 Apr;12(1):7–11.
22. Bello AK, Okpechi IG, Levin A, Ye F, Damster S, Arruebo S, et al. An update on the global disparities in kidney disease burden and care across world countries and regions. *Lancet Glob Health.* 2024 Mar;12(3):e382–95.
23. Ying M, Shao X, Qin H, Yin P, Lin Y, Wu J, et al. Disease Burden and Epidemiological Trends of Chronic Kidney Disease at the Global, Regional, National Levels from 1990 to 2019. *Nephron.* 2024;148(2):113–23.
24. Xie D, Ma T, Cui H, Li J, Zhang A, Sheng Z, et al. Global burden and influencing factors of chronic kidney disease due to type 2 diabetes in adults aged 20–59 years, 1990–2019. *Sci Rep.* 2023 Nov 19;13(1):20234.
25. Wei H, Ren J, Li R, Qi X, Yang F, Li Q. Global, regional, and national burden of chronic kidney disease attributable to high fasting plasma glucose from 1990 to 2019: a systematic analysis from the global burden of disease study 2019. *Front Endocrinol.* 2024 Mar 27;15:1379634.
26. Oguejiofor F, Kiggundu DS, Bello AK, Swanepoel CR, Ashuntantang G, Jha V, et al. International Society of Nephrology Global Kidney Health Atlas: structures, organization, and services for the management of kidney failure in Africa. *Kidney Int Suppl.* 2021 May;11(2):e11–23.
27. Levey AS, Stevens LA, Schmid CH, Zhang Y (Lucy), Castro AF, Feldman HI, et al. A New Equation to Estimate Glomerular Filtration Rate. *Ann Intern Med.* 2009 May 5;150(9):604–12.
28. Animaw Z, Walle Ayehu G, Abdu H. Prevalence of chronic kidney disease and associated factors among patients with chronic illness in Ethiopia: A systematic review and meta-analysis. *SAGE Open Med.* 2022 Jan;10:205031212210894.
29. Wilson S, Mone P, Jankauskas SS, Gambardella J, Santulli G. Chronic kidney disease: Definition, updated epidemiology, staging, and mechanisms of increased cardiovascular risk. *J Clin Hypertens.* 2021 Apr;23(4):831–4.
30. Wouk N. End-Stage Renal Disease: Medical Management. *Am Fam Physician.* 2021 Nov 1;104(5):493–9.

31. Sehgal AR. What is the best treatment for end-stage renal disease? *Am J Med.* 2002 Jun;112(9):735–6.
32. Bello AK, Okpechi IG, Osman MA, Cho Y, Htay H, Jha V, et al. Epidemiology of haemodialysis outcomes. *Nat Rev Nephrol.* 2022 Jun;18(6):378–95.
33. Kore C, Tadesse A, Teshome B, Daniel K, Kassa A, Ayalew D. The Magnitude of Chronic Kidney Disease and its Risk Factors at Zewditu Memorial Hospital, Addis Ababa, Ethiopia. *J Nephrol Ther* [Internet]. 2018 [cited 2024 Jul 9];08(03). Available from: <https://www.omicsonline.org/open-access/the-magnitude-of-chronic-kidney-disease-and-its-risk-factors-at-zewditu-memorial-hospital-addis-ababa-ethiopia-2161-0959-1000313-102570.html>
34. Gebrie MH, Asfaw HM, Bilchut WH, Lindgren H, Wettergren L. Patients’ experience of undergoing maintenance hemodialysis. An interview study from Ethiopia. Aoun M, editor. *PLOS ONE.* 2023 May 30;18(5):e0284422.
35. Tadesse H, Gutema H, Wasihun Y, Dagne S, Menber Y, Petrucka P, et al. Lived Experiences of Patients with Chronic Kidney Disease Receiving Hemodialysis in Felege Hiwot Comprehensive Specialized Hospital, Northwest Ethiopia. *Int J Nephrol.* 2021;2021:6637272.
36. Ogowang A, Murungi E, Vallence N, Esther B. Lived Experiences of Patients on Hemodialysis Treatment at Kiruddu National Referral Hospital: A Phenomenological Study. *Patient Relat Outcome Meas.* 2023 Dec;Volume 14:393–408.
37. Al-Talib M, Caskey FJ, Inward C, Ben-Shlomo Y, Hamilton AJ. Psychological Health in Young Adults With Kidney Failure: A 5-Year Follow-up of the SPEAK Study. *Kidney Med.* 2023 Jun;5(6):100637.
38. Kutner NG, Bowles T. Young-Adulthood Development in the Lived Experience of Persons With Kidney Failure: Challenges of Youth, Disability, and Transition. In: Dillaway HE, Shandra CL, Bender AA, editors. *Research in Social Science and Disability* [Internet]. Emerald Publishing Limited; 2023 [cited 2024 Nov 13]. p. 69–87. Available from: <https://www.emerald.com/insight/content/doi/10.1108/S1479-354720230000014005/full/html>
39. Tong A, Henning P, Wong G, McTaggart S, Mackie F, Carroll RP, et al. Experiences and perspectives of adolescents and young adults with advanced CKD. *Am J Kidney Dis Off J Natl Kidney Found.* 2013 Mar;61(3):375–84.

40. Japiong M, Landy CK, Fox MT, Mensah J, Adatar P. Factors affecting access to dialysis for patients with end-stage kidney disease in Sub-Saharan Africa: A scoping review. *Nurs Open*. 2023 Oct;10(10):6724–48.
41. Alfiler CA, Llanto EA, Anacleto, Jr. FE, Padilla CD, Bonzon DD, Montemayor ES. Adolescent Pediatric Kidney Patients Transitioned to Adult Health Care Services through the Philippine General Hospital (PGH) Transition Program (Lipat Kalinga). *Acta Med Philipp* [Internet]. 2013 Sep 23 [cited 2024 Nov 13];47(1). Available from: <https://actamedicaphilippina.upm.edu.ph/index.php/acta/article/view/2029>
42. Malik S, Allen RJ, Vachharajani TJ, Kluger B, Ahmad I, Saeed F. Dialysis Decision Making, Dialysis Experiences, and Illness Perceptions: A Qualitative Study of Pakistani Patients Receiving Maintenance Hemodialysis. *Kidney Med*. 2022 Nov;4(11):100550.
43. Kassa DA, Mekonnen S, Kebede A, Haile TG. Cost of Hemodialysis Treatment and Associated Factors Among End-Stage Renal Disease Patients at the Tertiary Hospitals of Addis Ababa City and Amhara Region, Ethiopia. *Clin Outcomes Res*. 2020 Jul;Volume 12:399–409.
44. Tinsae Semu, Million Abera, Yeshitila Belay. Lived Experience of Chronic Renal Disease Patients Who are on Hemo Dialysis: Phenomenological Study at Jimma University Medical Center, South West Ethiopia, 2022. *Jimma Univ Open Access Institutional Repos Exp Chronic Ren Dis Patients Who Are Hemo Dial Phenomenol Study Jimma Univ Med Cent South West Ethiop* 2022 [Internet]. 2022 Dec 5; Available from: <https://repository.ju.edu.et/handle/123456789/8577>
45. Joshi U, Subedi R, Poudel P, Ghimire PR, Panta S, Sigdel MR. Assessment of quality of life in patients undergoing hemodialysis using WHOQOL-BREF questionnaire: a multicenter study. *Int J Nephrol Renov Dis*. 2017;10:195–203.
46. Yonata A, Islamy N, Taruna A, Pura L. Factors Affecting Quality of Life in Hemodialysis Patients. *Int J Gen Med*. 2022;15:7173–8.
47. Sathvik BS, Parthasarathi G, Narahari MG, Gurudev KC. An assessment of the quality of life in hemodialysis patients using the WHOQOL-BREF questionnaire. *Indian J Nephrol*. 2008 Oct;18(4):141–9.

48. Ghaffari M, Morowatisharifabad MA, Mehrabi Y, Zare S, Askari J, Alizadeh S. What Are the Hemodialysis Patients' Style in Coping with Stress? A Directed Content Analysis. *Int J Community Based Nurs Midwifery*. 2019 Oct;7(4):309–18.
49. Dehkordi LM, Shahgholian N. An investigation of coping styles of hemodialysis patients. *Iran J Nurs Midwifery Res*. 2013 Jan;18(1):42–6.
50. Tu HY, Shao JH, Wu FJ, Chen SH, Chuang YH. Stressors and coping strategies of 20–45-year-old hemodialysis patients. *Collegian*. 2014 Sep;21(3):185–92.
51. Kisomi ZS, Taherkhani O, Mollaei M, Esmaeily H, Shirkhanloo G, Hosseinkhani Z, et al. The moderating role of social support in the relationship between death anxiety and resilience among dialysis patients. *BMC Nephrol* [Internet]. 2024 Mar 16 [cited 2025 Jul 11];25(1). Available from: <https://bmcnephrol.biomedcentral.com/articles/10.1186/s12882-024-03533-x>
52. Assefa Y, Hill PS, Gilks CF, Admassu M, Tesfaye D, Van Damme W. Primary health care contributions to universal health coverage, Ethiopia. *Bull World Health Organ*. 2020 Dec 1;98(12):894-905A.
53. Nair VD, Morankar S, Jira C, Tushune K. Private hospital sector development: an exploratory study on providers perspective in addis ababa, ethiopia. *Ethiop J Health Sci*. 2011 Aug;21(Suppl 1):59–64.
54. Sinfield G, Goldspink S, Wilson C. Waiting in the Wings: The Enactment of a Descriptive Phenomenology Study. *Int J Qual Methods*. 2023 Oct;22:16094069231207012.
55. Booth A, Hannes K, Harden A, Noyes J, Harris J, Tong A. COREQ (Consolidated Criteria for Reporting Qualitative Studies). In: Moher D, Altman DG, Schulz KF, Simera I, Wager E, editors. *Guidelines for Reporting Health Research: A User's Manual* [Internet]. 1st ed. Wiley; 2014 [cited 2024 Nov 13]. p. 214–26. Available from: <https://onlinelibrary.wiley.com/doi/10.1002/9781118715598.ch21>
56. Chung D. The Eight Stages of Psychosocial Protective Development: Developmental Psychology. *J Behav Brain Sci*. 2018;08(06):369–98.
57. M.Sc. Nursing final year, Teerthanker Mahaveer College of Nursing, TMU, Moradabad, U. P., Shah S, Chithra K, Assistant Professor, Teerthanker Mahaveer College of Nursing, TMU,

Moradabad, U. P. LIVED EXPERIENCE OF PATIENTS UNDERGOING HEMODIALYSIS. *Int J Adv Res.* 2017 Apr 30;5(4):1418–26.

58. Mrs. Rohini. T, Dr. Punitha. V. Ezhilarasu. Lived Experience of Patients Undergoing Hemodialysis: Quality of Life Perspective. *Int J Indian Psychol* [Internet]. 2016 Mar 25 [cited 2024 Jun 29];3(2). Available from: <https://ijip.in/articles/lived-experience-of-patients-undergoing-hemodialysis-quality-of-life-perspective/>

59. Shouket H, Gringart E, Drake D, Steinwandel U. “Machine-Dependent”: The Lived Experiences of Patients Receiving Hemodialysis in Pakistan. *Glob Qual Nurs Res.* 2022 Jan;9:23333936221128240.

60. Sah BK, Khan I, Dhungana A, Subedi M, Dhital R. Lived Experiences of Chronic Kidney Disease Patients undergoing Haemodialysis in a Tertiary Hospital of Nepal. *J Nepal Health Res Counc.* 2025 Feb 14;22(04):738–43.

61. Tafese ST, Abera EG, Mersha MD, Woldemariam MB. Clinical characteristics and outcomes of patients on haemodialysis at Jimma medical center, Ethiopia: a 7-Year review. *BMC Nephrol.* 2024 Nov 22;25(1):420.

62. Boateng EA, Iddrisu AA, Kyei-Dompim J, Amooba PA. A qualitative study on the lived experiences of individuals with end-stage kidney disease (ESKD) accessing haemodialysis in Northern Ghana. *BMC Nephrol.* 2024 May 31;25(1):186.

63. Eyowas FA, Schneider M, Alemu S, Getahun FA. Multimorbidity of chronic non-communicable diseases: burden, care provision and outcomes over time among patients attending chronic outpatient medical care in Bahir Dar, Ethiopia-a mixed methods study protocol. *BMJ Open.* 2021 Sep 8;11(9):e051107.

64. Gityamwi NA, Hart K, Engel B. A Cross-Sectional Analysis of Dietary Intake and Nutritional Status of Patients on Haemodialysis Maintenance Therapy in a Country of Sub-Saharan Africa. *Int J Nephrol.* 2021;2021:1826075.

65. Sualeheen A, Khor BH, Balasubramanian GV, Sahathevan S, Ali MSM, Narayanan SS, et al. Habitual Dietary Patterns of Patients on Hemodialysis Indicate Nutritional Risk. *J Ren Nutr.* 2020 Jul;30(4):322–32.

66. Epstein RM, Street RL. The values and value of patient-centered care. *Ann Fam Med*. 2011;9(2):100–3.
67. Kelley JM, Kraft-Todd G, Schapira L, Kossowsky J, Riess H. The influence of the patient-clinician relationship on healthcare outcomes: a systematic review and meta-analysis of randomized controlled trials. *PloS One*. 2014;9(4):e94207.
68. Halpern J. Empathy and patient-physician conflicts. *J Gen Intern Med*. 2007 May;22(5):696–700.
69. Jhamb M, Weisbord SD, Steel JL, Unruh M. Fatigue in Patients Receiving Maintenance Dialysis: A Review of Definitions, Measures, and Contributing Factors. *Am J Kidney Dis*. 2008 Aug;52(2):353–65.
70. P R, S M, I J, J M, F F, P C, et al. Anaemia in Patients on Haemodialysis Therapy in Dar es Salaam, Tanzania. *Int J Nephrol Kidney Fail* [Internet]. 2019 [cited 2025 May 2];5(4). Available from: <https://www.sciforschenonline.org/journals/nephrology-kidney/IJNKF181.php>
71. Bansal N, Artinian NT, Bakris G, Chang T, Cohen J, Flythe J, et al. Hypertension in Patients Treated With In-Center Maintenance Hemodialysis: Current Evidence and Future Opportunities: A Scientific Statement From the American Heart Association. *Hypertension* [Internet]. 2023 Jun [cited 2025 May 2];80(6). Available from: <https://www.ahajournals.org/doi/10.1161/HYP.0000000000000230>
72. Klein KR, Lingvay I, Tuttle KR, Flythe JE. Glycemic Management and Individualized Diabetes Care in Dialysis-Dependent Kidney Failure. *Diabetes Care*. 2025 Feb 1;48(2):164–76.
73. Kimmel PL, Peterson RA, Weihs KL, Simmens SJ, Alleyne S, Cruz I, et al. Psychosocial factors, behavioral compliance and survival in urban hemodialysis patients. *Kidney Int*. 1998 Jul;54(1):245–54.
74. Mushi L, Marschall P, Fleßa S. The cost of dialysis in low and middle-income countries: a systematic review. *BMC Health Serv Res*. 2015 Jun;15(1):506.
75. Heisler M, Vijan S, Makki F, Piette JD. Diabetes Control With Reciprocal Peer Support Versus Nurse Care Management: A Randomized Trial. *Ann Intern Med*. 2010 Oct 19;153(8):507–15.

76. Cukor D, Ver Halen N, Fruchter Y, Kimmel PL. Psychosocial Issues in Chronic Kidney Disease Patients. In: *Chronic Renal Disease* [Internet]. Elsevier; 2015 [cited 2024 Jun 29]. p. 229–36. Available from: <https://linkinghub.elsevier.com/retrieve/pii/B9780124116023000196>
77. Talson MD, Ferreira Da Silva P, Finlay J, Rossum K, Soroka KV, McCormick M, et al. Patient, Caregiver, and Provider Perspectives on Improving Provider-Patient Interactions in Hemodialysis: A Qualitative Study. *Can J Kidney Health Dis*. 2025 Jan;12:20543581241309986.
78. Meremo AJ, Ngilangwa DP, Mwashambwa MY, Masalu MB, Kapinga J, Tagalile R, et al. Challenges and outcomes of haemodialysis among patients presenting with kidney diseases in Dodoma, Tanzania. *BMC Nephrol*. 2017 Jul 4;18(1):212.
79. Japiong M, Landy CK, Fox MT, Mensah J, Adatar P. Factors affecting access to dialysis for patients with END-STAGE kidney disease in SUB-SAHARAN Africa: A scoping review. *Nurs Open*. 2023 Oct;10(10):6724–48.
80. Barsoum RS, Khalil SS, Arogundade FA. Fifty Years of Dialysis in Africa: Challenges and Progress. *Am J Kidney Dis*. 2015 Mar;65(3):502–12.
81. Ashu JT, Mwangi J, Subramani S, Kaseje D, Ashuntantang G, Luyckx VA. Challenges to the right to health in sub-Saharan Africa: reflections on inequities in access to dialysis for patients with end-stage kidney failure. *Int J Equity Health*. 2022 Sep 5;21(1):126.
82. Sułkowski L, Matyja A, Matyja M. Social Support and Quality of Life in Hemodialysis Patients: A Comparative Study with Healthy Controls. *Medicina (Mex)*. 2024 Oct 22;60(11):1732.
83. Nguyen AM, Vo LH. Mental health and quality of life in dialysis and transplant patients in Vietnam: a call for integrated care models. *Front Psychiatry*. 2025 May 6;16:1570138.

Annexes

SCHOOL OF GRADUATE STUDIES

ADDIS ABABA UNIVERSITY

COLLEGE OF HEALTH SCIENCES

SCHOOL OF PUBLIC HEALTH

DECLARATION

I hereby declare that this MPH thesis is my original work and has not been presented for a degree in any other university, and all sources of material used for this proposal have been duly acknowledged.

Name: Yonatan Bekele Teshome

Signature: 

Date: June. 2025

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

Name: Professor Mitike Molla

Signature: 

Date: June. 2025

Annex I: participant information sheet and consent form

Title of Research Study: Gratitude for living off a machine: Lived Experiences of patients aged 18 to 40 years with chronic kidney disease on Hemodialysis Treatment: A phenomenological Study

Introduction: My name is Yonatan Bekele a master student of general public health at Addis Ababa Universtiy, college of health sciences, school of public health. I am conducting research to investigate Lived Experiences of Young Adult Patients with Chronic Kidney Disease on Hemodialysis Treatment: A phenomenological Study for partial fulfillment of master degree. You have been selected to participate in this study, and this participant information sheet aims to provide you with all the necessary details about the study to assist you in making an informed decision about participating.

Objective of the Study: To explore and understand the Lived Experiences of Young Adult Patients with Chronic Kidney Disease on Hemodialysis Treatment

Study Procedures: If you choose to participate in this study, you will be invited to take part in an in-depth interview (IDI) lasting approximately 40 to 50 minutes. The interview will be conducted in the Amharic language, and with your consent, it will be audio-recorded for accuracy. The interview will be conducted in a confidential setting and will involve questions about your experiences with hemodialysis, your physical and emotional well-being, and any challenges or supports you have encountered during treatment.

The interview will be audio-recorded for transcription and analysis purposes. Your responses will be kept strictly confidential and used only for the purpose of this study.

Confidentiality and Data Handling: Your participation and responses will be kept strictly confidential. Any information that could identify you will be remove from the data to ensure your privacy. The data collected will and only be accessible to the research team and will be stored securely for the duration of the study. All findings from the study will be reported in aggregate form, ensuring that no individual can be identified in any publications or presentations resulting from this research.

Benefits and Risks: Participating in this study will show the real feelings of dialysis patients over going on their care. While there are no direct benefits to you, your participation may contribute to

advancing knowledge in this area. There are no foreseeable risks associated with participating in this study.

Voluntary Participation and Withdrawal: Your participation in this study is voluntary, and you have the right to withdraw at any time without providing a reason. Your decision to participate or withdraw will not affect your current or future healthcare services.

Consent: By agreeing to participate in the study, you indicate that you have understood the information provided in this Participant Information Sheet. If you agree to participate, please sign the attached consent form.

If you have any questions or concerns about the study, please feel free to contact the researcher at the provided contact information. Thank you for considering participation in this research study.

Researcher: Yonatan Bekele

Contact: +251932509106

yonatanbekeledialysis@gmail.com

Annex II: Consent form

I volunteer to participate in a research project conducted by Yonatan Bekele from Addis Ababa University, college of health sciences, school of public health. I will be one of 14 people being interviewed for this research.

1. My participation in this project is voluntary. I understand that I will not be paid for my participation. I may withdraw and discontinue participation at any time without penalty.

2. I understand that if I feel uncomfortable in any way during the interview session, I have the right to decline to answer any question or to end the interview.

3. Participation involves being interviewed by the primary investigator. The interview will last approximately 40-50 minutes. Notes will be written during the interview. An audio tape of the interview and subsequent dialogue will be made. If I don't want to be taped, I will not be able to participate in the study.

4. I understand that the researcher will not identify me by name in any reports using information obtained from this interview, and that my confidentiality as a participant in this study will remain secure. Subsequent uses of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions.

5. I understand that this research study has been reviewed and approved by the Institutional Review Board (IRB) of Addis Ababa University, college of health sciences, school of public health

6. I have read and understand the explanation provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

7. I have been given a copy of this consent form. _____

My Signature

Date _____

For further information, please contact: Yonatan Bekele +251932509106

yonatanbekeledialysis@gmail.com

Annex III: Verbal consent form

I have been provided with information about the research study titled “Lived Experiences of Young Adult Patients with Chronic Kidney Disease on Hemodialysis Treatment: A phenomenological Study”

I have been given the opportunity to ask questions and I understand the study's purpose, procedures, and potential risks or benefits.

I also understand that my participation is voluntary, and I can withdraw at any time without consequences. I understand that the whole conversation will be audio-recorded, and the information collected will be kept confidential and used only for research purposes.

I agree to participate in the study and provide my insights. I understand that by providing my verbal consent, I am indicating my willingness to participate in the study.

By signing below, the data collector acknowledges that the participant has provided verbal consent to participate in the study.

Data collector's Signature: _____

Date: _____

Annex IV: English version of the questionnaire

Section 1: socio demographic data

no	Questions	Response
1	Age	_____
2	sex	1.Female 2. Male
3	Residence	1.In addis ababa 2.Outside addis ababa
4	Marital status	1.Single 2.Married 3.Divorced 4.Widowed
5	Educational status	1.None 2.Primary 3.Secondary 4. Sceondary above
6	Occupation	1. Employed 2.Unemployed
7	Underlying disease	_____
8	Duration of hemodialysis	_____
9	Monthly income	_____
10		

Section 2: Guiding questions for the in-depth interview

Warm up questions:

- Can you tell me about yourself? What you do for a living, education, family status and so on
 - Why are you here today?
 - How often do you come here
1. can you tell me about the treatment you are getting?
 - Do you have other comorbidities? Can you tell me about them and the medication you are taking if any
 2. Can you tell me what it is like for you to be on hemodialysis?
 - a. Probe for his/ her feelings at health facility
 - b. At home,
 3. What treatments do you have?
 - a. Do you follow the treatment regimen prescribed for you
 - b. What do you feel about following the treatment regimen/ your medications as prescribed?
 4. Can you tell me about your feeding pattern?

- a. Are there any restrictions?
 - b. What are the recommended food and beverages?
 - c. What do you feel about the restrictions?

- 5. Now, can we discuss about your interaction with health workers:
 - a. What does your communication look like?
 - b. Is it as per your expectation?
 - c. What do you like about it/ what do you hate about it?
 - d. If you were in your health workers place, how would you communicate with your patients?

- 7. Based on your experience, what would you tell someone new to dialysis about the challenges of their treatment?

- 8. Are there times where you want to stay at home and leave everything to chance or God?
 - Can you explain the feeling

- 8. Is there anything else you would like to say about your experience as a person on hemodialysis?

Annex V: Amharic version of the consent forms and questionnaire

የተሳታፊ መረጃ ወረቀት እና የስምምነት ቅጽ

የምርምር ጥናት ርዕስ: ሥር የሰደደ የኩላሊት በሽታ ያለባቸው ወጣት ጎልማሳ ታማሚዎች በሄሞዲያሊስስ ሕክምና ላይ ያጋጠሟቸው ገጠመኞች፡ ፍኖሜኖሎጂካል ጥናት

መግቢያ: የናታን በቀለ እባላለሁ በአዲስ አበባ ዩኒቨርሲቲ፣ በጤና ሳይንስ ኮሌጅ፣ በሕዝብ ጤና ትምህርት ቤት የአጠቃላይ ማህበረሰብ ጤና ማስተር ተማሪ። ሥር የሰደደ የኩላሊት በሽታ ያለባቸው ወጣት ጎልማሳ ታማሚዎች በሄሞዲያሊስስ ሕክምና ላይ ያላቸውን የሕይወት ተሞክሮ ለመመርመር ጥናት እያካሄድኩ ነው። የማስተርስ ዲግሪን በከፊል ለመጨረስ የተፈጠረ ክስተት። በዚህ ጥናት ላይ ለመሳተፍ ተመርጠዋል፤ እና ይህ የተሳታፊ መረጃ ወረቀት ስለ ጥናቱ አስፈላጊ የሆኑትን ሁሉንም ዝርዝሮች ለእርስዎ ለማቅረብ ያለመ ስለመሳተፍ በመረጃ ላይ የተመሰረተ ውሳኔ ለማድረግ ነው።

የጥናቱ ዓላማ: በሄሞዲያሊስስ ሕክምና ላይ ሥር የሰደደ የኩላሊት በሽታ ያለባቸው ወጣት ጎልማሳ ታማሚዎችን የሕይወት ተሞክሮ ለመዳሰስ እና ለመረዳት

የጥናት ሂደቶች: በዚህ ጥናት ውስጥ ለመሳተፍ ከመረጡ፣ ከ40 እስከ 50 ደቂቃዎች በሚቆይ ጥልቅ ቃለ መጠይቅ (IDI) ላይ እንድትሳተፉ ይጋበዛሉ። ቃለ-መጠይቁ የሚካሄደው በአማርኛ ቋንቋ ነው፤ እና በእርስዎ ፈቃድ፣ ለትክክለኛነቱ በድምጽ ይቀዳል። ቃለ-መጠይቁ የሚካሄደው ሚስጥራዊ በሆነ ሁኔታ ሲሆን ከሄሞዲያሊስስ ጋር ስላለዎት ልምድ፣ ስለ አካላዊ እና ስሜታዊ ደህንነትዎ እንዲሁም በህክምና ወቅት ያጋጠሙዎትን ተግዳሮቶች ወይም ድጋፎች በተመለከተ ጥያቄዎችን ያካትታል።

ቃለ-መጠይቁ ለፅሁፍ እና ለመተንተን ዓላማዎች በድምጽ ይቀዳል። የእርስዎ ምላሾች በጥብቅ ሚስጥራዊ ይሆናሉ እና ለዚህ ጥናት ዓላማ ብቻ ጥቅም ላይ ይውላሉ።

ምስጢራዊነት እና የውሂብ አያያዝ: የእርስዎ ተሳትፎ እና ምላሾች በጥብቅ ሚስጥራዊ ይሆናሉ። እርስዎን የሚለይ ማንኛውም መረጃ የእርስዎን ግላዊነት ለማረጋገጥ ከውሂቡ ይወገዳል። የተሰበሰበው መረጃ ለተመራማሪው ቡድን ብቻ ተደራሽ ይሆናል እና ለጥናቱ ጊዜ ደህንነቱ በተጠበቀ ሁኔታ ይከማቻል። በጥናቱ የተገኙ ሁሉም ግኝቶች በአጠቃላይ ሪፖርት ይደረጋሉ፣ ይህም ማንኛውም ሰው በዚህ ጥናት ውስጥ በማንኛውም ህትመቶች ወይም አቀራረቦች ላይ ተለይቶ ሊታወቅ እንደማይችል ያረጋግጣል።

ጥቅሞች እና ስጋቶች: በዚህ ጥናት ውስጥ መሳተፍ የዲያሊስስን ህመምተኞች እንክብካቤ ሲያደርጉ ያላቸውን እውነተኛ ስሜት ያሳያል። ለእርስዎ ምንም ዓይነት ቀጥተኛ ጥቅሞች ባይኖሩም፣ የእርስዎ ተሳትፎ በዚህ አካባቢ እውቀትን ለማራመድ አስተዋፅኦ ሊያደርግ ይችላል። በዚህ ጥናት ውስጥ ከመሳተፍ ጋር የተያያዙ ምንም ሊታዩ የሚችሉ አደጋዎች የሉም።

በፈቃደኝነት ተሳትፎ እና መውጣት: በዚህ ጥናት ውስጥ ያለዎት ተሳትፎ በፈቃደኝነት ላይ የተመሰረተ ነው፣ እና በማንኛውም ጊዜ ያለምክንያት የማቋረጥ መብት አለዎት። ለመሳተፍ ወይም ለመውጣት ያደረጉት ውሳኔ የአሁኑን ወይም የወደፊት የጤና አጠባበቅ አገልግሎቶችን አይጎዳውም።

ስምምነት: በጥናቱ ለመሳተፍ በመስማማት በዚህ የተሳታፊ መረጃ ሉህ ላይ የቀረበውን መረጃ እንደተረዱት ያሳያሉ። ለመሳተፍ ከተስማሙ፣ እባክዎ የተያያዘውን የፍቃድ ቅጽ ይፈርሙ።

ስለ ጥናቱ ማንኛቸውም ጥያቄዎች ወይም ስጋቶች ካሉዎት፣ እባክዎን በተጠቀሰው የእውቂያ መረጃ ላይ ተመራማሪውን ለማነጋገር ነፃነት ይሰጣዎታል። በዚህ የምርምር ጥናት ውስጥ ለመሳተፍ ስላሰቡ እና መሰማሰን።

ተመራማሪ: የናታን በቀለ

አድራሻ: +251932509106

yonatanbekeledialysis@gmail.com

የፍቃድ ቅፅ

በዮናታን በቀለ ከአዲስ አበባ ዩኒቨርሲቲ፣ ከጤና ሳይንስ ኮሌጅ፣ ከህብረተሰብ ጤና ትምህርት ቤት ባደረገው የምርምር ፕሮጀክት ለመሳተፍ ፈቃደኛ ነኝ። ለዚህ ጥናት ከተጠየቁት 14 ሰዎች አንዱ እሆናለሁ።

1. በዚህ ፕሮጀክት ውስጥ የእኔ ተሳትፎ በፈቃደኝነት ነው። ለተሳትፎ ከፍታ እንደማይከፈለኝ ተረድቻለሁ። በማንኛውም ጊዜ ያለ ቅጣት መሳተፍን ላቋርጥ እና ማቋረጥ እችላለሁ።

2. በቃለ መጠይቁ ወቅት በምንም መልኩ ምችት የማይሰማኝ ከሆነ ማንኛውንም ጥያቄ ለመመለስ ወይም ቃለ መጠይቁን ለመጨረስ መብት እንዳለኝ ተረድቻለሁ።

3. ተሳትፎ ከዋናው መርማሪ ጋር ቃለ መጠይቅ ማድረግን ያካትታል። ቃለ መጠይቁ በግምት ከ40-50 ደቂቃዎች ይቆያል። በቃለ መጠይቁ ወቅት ማስታወሻዎች ይጻፋሉ። የቃለ መጠይቁ የድምጽ ካሴት እና ቀጣይ ውይይት ይደረጋል። መቅዳት ካልፈለግኩ በጥናቱ መሳተፍ አልችልም።

4. ተመራማሪው ከዚህ ቃለ መጠይቅ ያገኘሁትን መረጃ ተጠቅሞ በማናቸውም ዘገባዎች ላይ በስሜ እንደማይለይ ተረድቻለሁ። እናም የዚህ ጥናት ተሳታፊ እንደመሆኔ ሚስጥራዊነቴ የተጠበቀ ይሆናል። በቀጣይ የሚደረጉ መዝገቦች እና መረጃዎች የግለሰቦችን እና የተቋማትን ስም-አልባነት የሚከላከሉ መደበኛ የውሂብ አጠቃቀም ፖሊሲዎች ተገዢ ይሆናሉ።

5. ይህ የምርምር ጥናት በአዲስ አበባ ዩኒቨርሲቲ ተቋማዊ ግምገማ ቦርድ፣ በጤና ሳይንስ ኮሌጅ፣ በህብረተሰብ ጤና ትምህርት ቤት ታይቶ ተቀባይነት እንዳገኘ ተረድቻለሁ።

6. የተሰጠኝን ማብራሪያ አንብቤ ተረድቻለሁ። ለጥያቄዎቼ ሁሉ እርካታ አግኝቻለሁ። እናም በዚህ ጥናት ለመሳተፍ በፈቃዴ ተስማምቻለሁ።

7. የዚህ የስምምነት ቅጽ ቅጂ ተሰጥቶኛል። _____

የእኔ ፊርማ _____ ቀን _____

ለበለጠ መረጃ፡ ዮናታን በቀለን +251932509106 ያግኙ
yonatanbekeledialysis@gmail.com

የቃል ስምምነት ቅጽ

“የወጣት ጎልማሳ ታማሚዎች ሥር የሰደደ የኩላሊት በሽታ ያለባቸው በሄሞዲያሊስስ ሕክምና ላይ ያጋጠሙኝ የሕይወት ተሞክሮ፡ ፍኖሜኖሎጂካል ጥናት” በሚል ርዕስ ስለተደረገው የምርምር ጥናት መረጃ ተሰጥቶኛል።

ጥያቄዎችን እንድጠይቅ እድል ተሰጥቶኛል እና የጥናቱን አላማ፣ አካሄዶች፣ እና ሊኖሩ የሚችሉ ስጋቶችን ወይም ጥቅሞችን ተረድቻለሁ።

የእኔ ተሳትፎ በፈቃደኝነት እንደሆነም ተረድቻለሁ፣ እና በማንኛውም ጊዜ ያለምንም መዘዝ ማቋረጥ እችላለሁ። ንግግሩ በሙሉ በድምጽ እንደሚቀረፅ እና የሚሰበሰበው መረጃ በሚስጥር እንደሚጠበቅ እና ለምርምር ዓላማዎች ብቻ እንደሚውል ተረድቻለሁ።

በጥናቱ ለመሳተፍ እና ግንዛቤዬን ለማቅረብ ተስማምቻለሁ። የቃል ፈቃዴን በመስጠት በጥናቱ ለመሳተፍ ፈቃደኛ መሆኔን እያሳየሁ እንደሆነ ተረድቻለሁ።

ከዚህ በታች በመፈረም መረጃ ስብሰቢው በጥናቱ ላይ ለመሳተፍ የቃል ፈቃድ መስጠቱን ይቀበላል።

የመረጃ ስብሰቢ ፊርማ፡- _____

ቀን፡- _____

ተ.ቁ	ጥያቄ	መልስ
1	ዕድሜ	
2	ጾታ	1. ሴት 2. ወንድ
3	መኖሪያ ስፍራ	1. በአዲስ አበባ 2. ከአዲስ አበባ ውጪ
4	የጋብቻ ሁኔታ	1. ነጠላ 2. ያገባ 3. የተፋታ 4. መበለት
5	የትምህርት ደረጃ	1. የለም 2. የመጀመሪያ ደረጃ 3. ሁለተኛ ደረጃ 4. ከሁለተኛ ደረጃ በላይ
6	የስራ ሁኔታ	1. የተቀጠረ 2. ስራ አልባ
7	ተጋዳኝ ህመም አለብዎ	
8	የሄሞዲያሊስስ የህክምና ጊዜ ርዝመት	
9	ወርሃዊ ገቢ	
10		

ክፍል 2፡ ለጥልቅ ቃለ መጠይቁ መሪ ጥያቄዎች

- ስለራስዎ ሊነግሩኝ ይችላሉ? ስለኑሮ ፣ ስለትምህርት ፣ ስለቤተሰብ ደረጃ እና ስለልጅ

- ዛሬ ለምን መጡ?

- ምን ያህል ጊዜ ወደዚህ ይመጣሉ

1. ስለምታገኙት ሕክምና ልትነግሩኝ ይችላሉ?

o ሌሎች ተላላፊ በሽታዎች አሎት? ካለ ስለእነሱ እና ስለሚወስዱት መድሃኒት ሊነግሩኝ ይችላሉ።

2. በሄሞዲያሊስስ ላይ መሆንዎ ምን እንደሚመስል ሊነግሩኝ ይችላሉ?

ሀ. በጤና ተቋም ውስጥ ስላለ ስሜት

ለ. ቤት ውስጥ፣

3. ምን ዓይነት ሕክምናዎች አሉዎት?

ሀ. ለእርስዎ የታዘዘውን የሕክምና ዘዴ ይከተላሉ

ለ. በታዘዘው መሰረት የሕክምናውን ስርዓት ስለመከተል ምን ይሰማዎታል?

4. ስለ አመጋገብ ስርዐትው ሊነግሩኝ ይችላሉ?

ሀ. እገዳዎች አሉ?

ለ. የሚመከሩ ምግቦች እና መጠጦች ምንድናቸው?

ሐ. ስለ እገዳዎቹ ምን ይሰማዎታል?

5. አሁን፣ ከጤና ሰራተኞች ጋር ስላለው ግንኙነት መወያየት እንችላለን፡-

ሀ. የእርስዎ ግንኙነት ምን ይመስላል?

ለ. እንደጠበቁት ነው?

ሐ. ስለሱ ምን ይወዳሉ / ስለሱ ምን ይጠላሉ?

መ. በጤና ሰራተኞችዎ ቦታ ቢሆኑ ከታካሚዎችዎ ጋር ሚኖርዎት ግንኙነት ምን ዓይነት ሊሆን ይችላል?

7. ከተሞክሮዎ በመነሳት ለዲያሊስስ አዲስ ለሆነ ሰው ስለ ህክምናው ተግዳሮቶች ምን ይነግሯቸዋል?

8. በቤት ውስጥ ለመቆየት እና ሁሉንም ነገር ለአጋጣሚ ወይም ለእግዚአብሔር ለመተው ያሰቡበት ጊዜ አለ?

o ስሜቱን ማብራራት ትችላለህ

8. እንደ ሰው ሄሞዲያሊስስን በተመለከተ ስላለዎት ልምድ መናገር የሚፈልጉት ሌላ ነገር አለ?

Annex VI: Consolidated criteria for reporting qualitative studies (COREQ) checklist

Table 5: COREQ checklist

no	Guide questions	Report to be
1	Which authors conducted the interview or the focus group?	PI
2	What were the researcher's credential's?	MPH candidate
3	What was their occupation at the time of the study?	Student
4	Was the researcher male or female?	Male
5	What experience or training did the researchers have?	Lessons in school
6	Was a relationship established prior to the study commencement	Yes
7	What did the participants know about the researcher? E.g. personal goals, reasons for doing research	The researcher was a post graduate student doing his master's degree. And that the researcher was also a fellow patient
8	What methodological orientation was stated to underpin the study?	Descriptive phenomenological study
9	How were participants selected?	Purposive sampling
10	How were participants approached?	Through healthcare providers
11	How many participants were in the study?	17
12	Where was the data collected?	At the dialysis center
13	What are the important characteristics of the Sample?	Are patients who have been on dialysis for more than six months
14	Were questions, prompts, guides provided by the authors? Was it pilot tested?	No
15	Were repeat interviews carried out? If yes, how many?	No
16	Did the research use audio or visual recording to collect the data?	Audio
17	Were field notes made during and/or after the interview or focus group?	Yes
18	What was the duration of the interviews or focus groups?	40-50 minutes
19	Was data saturation discussed?	Yes
20	How many data coders coded the data?	3
21	Did authors provide a descriptions of the coding tree?	Yes
22	Were themes identified in advance or derived from the data?	Derived from the data
23	What software, if applicable, was used to manage the data	OpenCode 4.0
24	Did participant provide feedback on the finding?	Yes
25	Were participant quotations presented to illustrate the themes/findings? Was each quotations identified? E.g. participant number	Yes

26	Was there consistency between the data presented and the findings	Yes
27	Were major themes clearly presented in the findings	Yes

Annex VII: Code Book

Table 6:code book

Physical and emotional experience	Signs and symptoms including nausea, vomiting, fatigue, anxiety and depression that resulted from dialysis
Financial experience	Any expense associated with dialysis and other comorbidities related to dialysis or otherwise
Availability, accessibility and efficiency of healthcare	Existence of dialysis centers, the distance from home and availability of working machines and personnel
Experiences associated with caregivers	Feelings patients show and have towards their family member, friends or others who take care of them
Perceived effectiveness and gratitude for treatment	Feeling of relief after dialysis, being thankful for having access and treatment
High prevalence of comorbid conditions	Any health-related condition that came because of chronic kidney disease
Underlying causes and secondary diagnoses	Any health-related condition that brought about chronic kidney disease
Lifestyle modifications	Changes patient had to undergo as a result of having started dialysis related to their day-to-day activities including eating and drinking habits, exercise, clothing and the like
Treatment adherence	Sticking to regular dialysis sessions, medications ordered and follow-ups
Diet and nutrition	Eating habits of patients and the effect it has on maintaining their health and nutritional status
Interaction with healthcare workers	Relationships patients have and built with their doctors, nurses and other health care workers within the dialysis center
Physical and emotional challenges	Challenges patients face and have to overcome as a result of having physical and emotional experiences defined in the physical and emotional experiences section
Economic challenges	Challenges faced by patients and patients struggle with that are described in the financial experiences section

Social challenges	Challenges such as loneliness, discrimination, misunderstandings and the like patients face while living within society as dialysis patients
Coping mechanisms	Mechanisms put in place by patients that help them cope with, fight against and persevere while going through the different challenges and experiences they face while they are undergoing dialysis
Health care providers view on patients' challenges	Different challenges patients go through that are noticed by health care providers.
Challenges in providing dialysis	Challenges such as lack of awareness, lack of supplies, inaccessibility, lack of professionals and the like that are hindering dialysis providers from providing enough services
Accessibility and affordability	Can health care providers provide dialysis services with ease? Do health care providers think the service they provide is affordable and accessible?
Support	Advices, physical help, psychological help, emotional help, and such other that health care providers provide for patients
Opinions from patients	Feedbacks given to health care providers by patients during their stay in the dialysis center or through other means of communications and opinions patients develop after having spent time on dialysis by their own.

Annex VIII: Curriculum vitae of the primary investigator

CURRICULUM VITAE

Yonatan Bekele Teshome (Bsc. In public healath, MPH candidate)

PERSONAL DATA

Home Address: Zewditu street, Kirkos Sub City, House number 858

Telephone: +251932509106

Email: yonatanbekeledilaysis@gmail.com

EDUCATION AND TRAINING

Year	Institution and certification
2023-2025	Master of public health candidate, Addis Ababa University, College of health sciences
2018-2022	Bsc in public health, Kea Med College
2008-2011	Highschool diploma, Lideta Catholic Cathedral School

Short courses

Year	Institution	Courses
April, 2025	FAO eLearning Academy	Voluntary National Reviews and the High-level Political Forum
December 2024, ongoing	BVGH and AORTIC	AAI Introduction to Common Cancers in the Community digital training program
October, 2024	BVGH	Basics of clinical trial management digital course
August, 2024	Addis Ababa University, school of commerce	Project management

PROFESSIONAL EXPERIENCE:

Position Title	Employer	Date
Founder and CEO	Miracle Foundation Ethiopia	2019 to date
Founder and CEO	Miracle Health care	2020 to date
Board member and Project Manager	Miracle Eats	2022 to date
Project Manager	Blessings to Wishes	2022 to date

