



# Lived Experiences of Patients on Hemodialysis Treatment at Kiruddu National Referral Hospital: A Phenomenological Study

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**Background:** There is increasing number of patients undergoing hemodialysis globally. Patients on hemodialysis experience physical and emotional stress due to the changes brought by chronic kidney disease.

**Aim:** The study aimed at exploring the lived experiences of patients on hemodialysis treatment in Kiruddu National Referral Hospital.

**Methods:** The study employed a phenomenological design. Data was collected using audio tape recording of the interview from 9 participants selected through purposive sampling at Kiruddu National Referral Hospital. The thematic aspects of the lived experience were uncovered using Van Manen data analysis which included three approaches: the detailed or line-by-line approach, selective or highlighting approach and holistic approach.

**Results:** Six themes emerged during the analysis as hemodialysis prolongs survival; hemodialysis is indispensable, family financial support, physical limitations, emotional distress and adaptation.

**Conclusion:** It was concluded from the findings that the patients undergoing haemodialysis are facing a wide range of problems such as physical and emotional problems during the course of their treatment and think that haemodialysis is the only way of survival, and these problems need to be addressed. Understanding gained in this study can help nurses to utilize this information in improving the quality of nursing care and guide patients to provide positive reinforcement for their future living.

**Keywords:** lived experiences, hemodialysis, phenomenology, adaptation

## Introduction

The only treatment for kidney or end-stage renal disease (ESRD) is dialysis or kidney transplant.<sup>1</sup> Patients treated with hemodialysis (HD) are a special group of chronically ill, who are at risk of frequent hospitalizations and multiple disorders due to renal dysfunction and to the HD treatment itself.<sup>2</sup> The number of people needing hemodialysis or transplants has been growing over the past 30 years.<sup>3,4</sup> A study conducted in Wakiso district of Uganda revealed a high prevalence of kidney disease of 15.2% and CKD of 2.5% with ESRD of 0.1% that reflects the increasing rate of ESRD in middle- and low-income countries with little available treatment in the low-income countries.<sup>5</sup> Dialysis is utilized more than kidney transplantation for treatment of ESRD in the majority of countries.<sup>6</sup> For those in low-income countries fortunate enough to receive hemodialysis, the patients must make many alterations in their lifestyles in order to maintain a reasonable level of wellness. Strict adherence to the treatment regimen is necessary, as are immediate and severe dietary and fluid restrictions.<sup>7</sup> In many cases, patients on hemodialysis without the ability to work must find new and creative ways to financially sustain themselves and their families. The psycho-social issues are enormous.

Wambi<sup>8</sup> noted that Ugandan adults aged 20 to 50 years seeking care at Mulago National Referral Hospital (MNRH) have a high prevalence of kidney disease. Notably, government health care for end-stage or kidney-related complications can only be found at the National Referral Hospital in Kampala. Thus, many patients have to travel long distances to access the services at the unit. Similarly, the problem of access is further compounded by the few hemodialysis machines

(33) for a total population of about 36 million people. Kiruddu National Referral Hospital (KNRH), where dialysis is done, has only 19 machines and country wide there are additional 26 machines in private facilities.<sup>9</sup> Another major challenge for hemodialysis in Uganda is paying the cost of 40 US dollars per week. Most patients do not have these resources, especially if it is necessary for several months or years and is a considerable distance from their homes.<sup>9</sup>

The experiences encountered by patients with chronic kidney disease (CKD) undergoing maintenance haemodialysis have been studied in many qualitative studies around the world. However, there is still limited qualitative synthesis yet which examined the experiences of these patients and their life situations based on their own perspective in Uganda. Hence, the investigator felt the need to explore the lives of patients undergoing haemodialysis in end-stage renal disease in Uganda through a thematic synthesis.

## Methodology

### Study Setting

The study was conducted at Kiruddu National Referral Hospital (KNRH) located in Makindye division, a suburb of Kampala. Kiruddu National Referral Hospital in July 2019 became an independent national referral hospital from Mulago National Referral Hospital. The hospital has a 170-bed capacity and receives in-patient admissions of approximately 750 to 1050 monthly. The hospital offers a wide range of curative, preventive and specialized care in hemodialysis treatment. Patients are referred to the hemodialysis unit from KNRH medical departments and other health centers in the region and across the country. According to the Health Management Information System (HMIS) report #108 of the monthly admissions, March 2020, 211 had kidney disease and 29 required dialysis. Out of 29 who required dialysis only 7 received hemodialysis. The hospital is the only large center for hemodialysis in Uganda, and offers specialized services and referrals.

### Research Design

The research is a qualitative descriptive design utilizing the phenomenological approach. The Husserl's phenomenological approach was utilized because it facilitates descriptions of situations from persons who experience them in the manner in which they are experienced.<sup>10</sup>

### Study Population

Participants were selected from the adult patients at KNRH receiving hemodialysis in both the inpatient and outpatient settings. The number of new patients who are enrolled on hemodialysis is 5 per month, and the total number of old cases receiving hemodialysis treatment in KNRH is 146 patients.

### Sample Size

The sample size for this study was 9 Participants as determined by saturation point. The emphasis was put on the richness of the data collected rather than the number of subjects. The sample size was determined basing on the study objective and ideologies arising from the subsequent interview. Sampling was continued until theoretical saturation or information redundancy was reached. Nine participants were recruited and participated in the study.

### Sampling Method

Purposive sampling of the study population was employed in this study. This method selects participants who are deemed information-rich about the phenomenon under study,<sup>11</sup> thus allowing understanding of the experience under investigation. The participants were selected according to the research purpose and the sample selection continued until the researcher recognized no new data was forth coming (data saturation).<sup>12</sup> The procedure involved identification of eligible participants, who are dependent on hemodialysis treatment. It included both inpatient and outpatient individuals. Both sexes and a variety of ages were included to provide a more global viewpoint.

## Inclusion Criteria

Diagnosed CKD patients aged 18–60 years that have completed a minimum of six months of hemodialysis and are still receiving hemodialysis. Those that have received dialysis for 6 months are targeted because they are assumed to have more experiences and can provide rich information on hemodialysis than their counter parts who have received dialysis for less than 6 months.

Those who were able to participate in the interviews and were willing to provide information about their perception of undergoing hemodialysis.

Those who consented to the study.

## Exclusion Criteria

Those who were restless felt significant fatigue and had very high blood pressure during dialysis. Also, patients who were delirious, unable to provide verbal information, seriously ill patients admitted to ICUs and patients identified as critical were excluded from the study.

## Data Collection

After receiving ethical approval from Research Ethics Committee (REC) 04/06-20 and administrative clearance from the Hospital Director of KNRH, the researcher contacted the head of the hemodialysis unit. With the researcher request, the head of the department notified the nurse in-charge about the study. Individuals receiving hemodialysis were selected for an interview based on the research sample criteria and in consultation with the staff of the unit. Recruitment of participants occurred with the assistance of the unit in charges of the hospital; participants were recruited from three units ie, the outpatient dialysis unit (Level.8), in patient renal unit (Level.5) and outpatient renal clinic (Level.1). Participants were assured that the information obtained from them would be treated with the utmost confidentiality and that information obtained from them would be published; therefore, their names and titles were not required and written informed consent was obtained to participate in the study. Further, this study complies with the Declaration of Helsinki of 1964 as it does not breach any confidentiality.

For this study, lived experience data were better gathered through narrative interviews as provided by the participants. These narratives were then converted into texts and interpreted to elicit meanings ascribed to the experiences by the participants.

The study purpose was explained to the selected participants, and written consents were obtained and consent to publish the findings also included which they agreed to in written consent form. A time convenient to the patient was selected for the interview in the hospital. The participants were interviewed when they were off the dialysis machine. They were interviewed in a comfortable place where no interruptions and privacy were guaranteed.

The respondents were assured of complete confidentiality to avoid biased information. Individual interview was considered appropriate to achieve the objectives of the research. No participant invited to participate declined.

The interviews commenced with the introduction of the researchers and social conversation in an attempt to build trust, creating rapport and a peace of mind.<sup>13</sup> The length of the interview was guided by the process of saturation that is when the interview became repetitive and no new data was revealed. There was ongoing data review by the researchers to identify new themes introduced by the participants.

The interviews lasted between 40 and 60 minutes. Both the first and second authors, who were trained in in-depth interviewing method and were postgraduate students with a Masters in Nursing Science in Critical care Nursing, performed the interviews at KNRH in the dialysis conference meeting room and away from patient care rooms over a 2 or 3-day period. Each participant was interviewed individually and thus his time compensated later, without other participants being present. Four authors coded the data. Some socio-demographic variables including age, sex, marital status, educational level, were extracted from patients' medical records.

The fourth author selected the interviewees using a purposeful sampling method. Purposeful sampling allows in-depth interviews with patients that are assumed to be rich sources of information. Before the interviews, the study's aim was described to the participants. So, the participants knew the researcher's role and the reasons for the study were disclosed

during the informed consent process. In the first session, both interviewers were introduced to the patients by the fourth authors to explain the reasons for the research. However, no relationship with the participants was made before the study began. The participants did not belong to specific political or social parties and were interested in the research topic. Of the 11 primary selected patients, two of them refused to participate in the study due to having no time to interview. The first two researchers were postgraduate students of nursing and the other two are lecturers in the Nursing department of Mbarara university of Science and Technology. Specific characteristics of the researchers may have an influence on data and analysis. Nevertheless, we established strict protocols to carry out the interviews and analysis of the data to reduce bias. Except for the first and second authors, other authors were faculty members/Lecturers. Two of them were male, and the other two were female. As the main aim of researchers in the phenomenological studies was the transformation of data to the lived experience, interviewers tried to bring individual experiences into phrases and attempted to understand those experiences based on the participants' statements. The interviews continued until it was clear that no additional concepts or themes were emerging. The sampling proceeded until data saturation.<sup>14</sup> Disagreements were discussed by the two interviewers until consensus was reached. In addition, Boyd et al consider 2 to 10 participants as adequate to reach saturation<sup>15</sup> and Creswell et al suggest "long interviews with up to 10 people" to conduct a phenomenological study.<sup>16</sup> Therefore, the selection of the 9 patients to perform this study was adequate. MAXQDA software was used for data management. We followed the COREQ checklist to ensure the rigor in our study "[Supplementary Table 1](#)".<sup>17</sup> Data was collected by semi-structured interviews. The interview is one of the common methods, which is conducted in structured, semi-structured, or unstructured style.<sup>18</sup> We asked some open questions such as: "What do you know about medical treatment of filtering fluids and waste products from blood?", "What is your opinion on medical treatment of filtering fluids and waste products from blood?", "What is it like to live with a CKD and depend on the machine for treatment", and "What feelings and emotions did you experience during your medical treatment of filtering fluids and waste products from your blood?" "How do you feel about frequenting the hospital for dialysis?" "Do you still have hope or confidence about your husband or he may leave you?" "Do you feel that something has changed because of dialysis?" "What are some of your fears in life?" "How about your spiritual life?" "How about the psychological aspect/feelings?" "Did you accept when they identified you with kidney disease?" This type of interview made it possible for personal experiences to be broadly and freely expressed. Essential skills for conducting interviews are paraphrasing, clarification, summarizing, and reflecting the feelings freely.<sup>18</sup> Limited probing questions were raised during the interviews for clarification, for instance "What do you mean by this statement?", "Please give an example", "Why?" or "Please elaborate or explain".<sup>18</sup>

## Data Management

All interviews were transcribed verbatim. The data recorded were then translated into English. The English translation was used in the analysis. The interview data were reviewed as it is completed to maximize obtaining the data needed, new directions of the interview based on received information as necessary, and information saturation. This review influenced the purposive selection of the respondents to ensure data saturation.

The transcripts and the audio recordings were safely stored in a password protected computer, to prevent unauthorized personnel to access the files and to maintain the confidentiality of the information. No name was associated with the transcripts per se, only the code assigned to decrease the chance of violating confidentiality.

## Data Analysis

Thematic analysis was done.<sup>19</sup> The thematic aspects of the lived experience were uncovered using Van Manen data analysis which included three approaches: the detailed or line-by-line approach, selective or highlighting approach and holistic approach.<sup>20</sup> After the completion of each interview, the recording was listened to several times to appreciate the content and the researcher transcribed the tapes. This transcription process helped immerse the researcher in the data and helped the researcher to think about what the interviewees were saying and how they were saying it. This process of transcribing and listening also prompted additional questions for a subsequent interview. The data collected was reviewed as the interviews are completed. This preliminary analysis was to help to shape the later data being collected and to give feedback to interviewers.

The detailed or line-by-line approach: Here, the verbatim transcribed data in English of each participant was read and re-read while listening to the corresponding audio tape to ensure accuracy of the transcribed tape. It was also read many times to get closer and more familiar expressions of the participants and to come to the overall understanding of the expressed meaning of each participant's experience and to identify the common issues that recur.

In the selective or highlighting approach, the text was read several times and the phrases that appear to be revealing about the phenomenon were underlined or highlighted. The codes were identified by highlighting materials in the interview text that spoke to each patient's experience. Subsequently, the researcher selected each of these highlighted sentences or phrases and tried to capture as fully as possible what meaning the highlighted material conveyed. The key words gained were then formulated into categories, sub-themes and themes representing the meanings of the participants' statement.

In the holistic approach, the researcher continued to re-read all the verbatim texts of each participant to find out themes of the texts.

Following the initial readings and preliminary identification of themes in each of the interviews, the researchers met with other members of the research team who were involved in the process of coding to discuss the themes in any areas that needed more investigations. The meeting helped to ensure that the researchers were on track and for the themes to be refined. The meeting involved examining and organizing the information contained in each interview and the whole dataset. This encouraged comparison, discussion and reaching consensus on the differences in the meaning of those codes and emerging patterns. Next, the researchers compared the themes in each interview, looked for commonalities and differences, and identified the overall themes that best described the experiences of these patients dependent on hemodialysis.

With the themes identified, the researcher then started the process of writing the themes and describing how they were interrelated. Rewriting proceeded until the researcher felt the themes and the relationship between the themes captured as accurately as possible the way these patients experienced hemodialysis. Data were analyzed using the Hermeneutic approach developed by Van Manen (1990), under seven categories as follows.

Narration: The data were written as narrative texts.

- Interpretation: The texts were reviewed several times to enable interpretation.
- Coding: Each statement was coded after a thorough interpretation.
- Sub-themes: Similar coded statements were categorized into sub-themes.
- Themes: Relevant sub-themes were used to form distinct themes.
- Stories: Groups of themes were combined to develop Stories.
- Assessment: We critically assessed the rigor of the stories by both the authors and an external reviewer.

The story rigor was assessed by Lincoln and Guba's criteria,<sup>21</sup> for being credible, dependable, confirmable, and transferable. We also held regular meetings to interview and consult the patients, asking them to read and check the subthemes and themes derived from the deliberations. Finally, the patients had the opportunity to confirm, clarify or reject the stated themes and concepts. Also, additional contacts made between the story authors and patients over the subsequent four months enhanced the credibility of the statements. The dependability of the statements was checked after recording, transcribing, and analyzing the interview contents. Further, the data were analyzed for consistency following the interviews. The confirmability was established based on the objectivity level of the data. To enhance this process, we developed an audit system to record the deliberations at each session throughout the study. The transferability was addressed by carefully recording the descriptions of the patients' lived experiences. At the end of the study, we provided feedback on the findings to the participant.

## Results

### Demographic Characteristics of Participants

In this study, the total number of patients who participated was 9 (nine). The number of males and females were 5 and 4, respectively. Most participants ranged between the ages of 18–30 years and had attained secondary education. Four

participants had taken 6 months to less than 1 year on dialysis and four of them had taken 1–5 years. Only 1 participant had taken more than 10 years on dialysis.

In this study, Hemodialysis prolongs survival, Hemodialysis is indispensable, Family financial support, Physical limitation, Emotional distress and Adaptations emerged as the main themes.

## Individuals' Perception of Their Illness (ESRD) and Hemodialysis That They are Receiving

### Hemodialysis Prolongs Survival

This theme explored the understanding of patients that hemodialysis prolongs their survival. This theme was described in three descending subthemes which are: clears body of toxins, prolong life and feels better.

#### Clears Body of Toxins

Participants mentioned that hemodialysis helps clear body of toxins using machines that do the same function as the kidneys. These toxins can be some waste that the kidneys cannot clear like urea, creatinine and excess water which is accumulated in the body which would otherwise make their blood pressure rise and they would feel bad. As one participant stated

...it is something that is just to help me remove some wastes that my kidneys cannot do, yah.... so it helps me, it has to help and do the work of kidney to remove the wastes like urea, creatinine and some other excess water which is accumulated in the body.  
(R.4, Male, 21 years)

#### Prolong Life

These patients realized that with dialysis life can be prolonged. It cannot heal them of the kidney problems. Kidney transplantation is the only way they will be cured. As one participant said

They are prolonging your life. Aah from literature I have read and I have seen that people can stay for at least 20 years but some people have stayed for 40 years on dialysis but this goes with a cost also, the client must also be discipline.... (R.1, Male, 54 years)

#### Feels Better

Participants mentioned that with dialysis someone can get improvement and feels better. The participants also noted that after dialysis one may not notice that the toxins have been removed but psychologically you feel you are better. As stated by one participant

It reduces the swellings, you get some improvement when you start it because by the time I started I was swollen the whole body, I couldn't even move, I am no longer swelling now (touching the feet). I couldn't talk; I could be admitted each and every second which is not there. (R.5, Female, 27 years)

### Hemodialysis is Indispensable

This theme provides the opinions of patients about hemodialysis. This theme was described in three descending subthemes as dialysis is good, promotes living and symptoms subsides.

#### Dialysis is Good

This was acknowledged by participants when they said that dialysis is good because it clears dangerous toxins and excess water from the body. When a patient is on dialysis he/she can still continue with his/her work. Some patients are suggesting that more machines should be secured and taken to their villages because coming to Kampala for dialysis is expensive. As one participant said

...in my own opinion dialysis is good because it will help clear away dangerous toxins and water from your body. (R.3, Male, 33 years)



## In Order to Live

The participants stated that dialysis sustains their lives. This enables them to continue doing the work that they could not do without it. The participants realized that all efforts should be towards dialysis because the moment you stop dialysis you will die. The importance of dialysis the participants feel must be explained to the family. As one participant said

When I do not dialyze then all the impurities will remain in me and then you will see me swelling up. And of course the next step is the potassium will block the heart and you will keep quite (meaning to die). (R.1, Male, 54 years).

## Symptoms Subsides

The participants noted that dialysis can help clear the symptoms of CKD like swelling and tiredness. They said this could improve their lives for example; those who could not do activities of daily living could do them after dialysis. As it was reported by one of the participants

...you feel relieved like you feel the other heaviness of the water in the body is gone mmh... that is it. Because it just removes the water and wastes, whenever they are in the body you feel bad, the pressure goes high, so it just relieves somehow. (R.8, Female, 25 years)

## Lived Experiences and Challenges of Individuals Receiving Hemodialysis

### Economic

#### Family Financial Support

This theme of family financial support on payment of medical bills was described in four descending subthemes as being paid by children, Payment done by parents, relatives and being sponsored. Payment was important because it came up as the concern by most participants and this roused from the engagement of a researcher with the text as she attempts to address a particular research question.

#### Paid by Children

Participants reported that payment was done by their sons and others by their daughters. This was stated by one participant:

I have my son who is a strategic planner with oil and gas who is paying for my medical bill but sometimes he has problems because he has a family also and dialysis is a continuous process and treating other infections which comes. (R, 2, Female, 60 years)

#### Payment Done by Parents

Payment for some patients was done by parents who were understanding. Some participants were being assisted by their fathers or mothers: This was illuminated from participants as

—————it is a help of my father who is a teacher, he use his salary to buy medicines, no one else helps me. (R.4, Male, 21 years).

#### Paid by Relatives

Relatives who have some good income understand difficulties of patients who get dialysis and help them in any way possible. One of the participants reported

I get the support from the family members mostly my sister who follows me since I am the first born. I pay 60,000Shs when I come, my sister tries to support me but at times you find that you have spent like three weeks without single pay. (R.5, Female, 27 years)

#### Being Sponsored Through Family Members

Dialysis is very expensive because it is a procedure that once a patient is started on it, it has to continue.

Some patients who are not able to pay die before their time. However, some are very lucky and are able to get sponsors as indicated by one participant:

These days I have got a sponsor to pay for my basic fee for dialysis though other requirements like transport and buying drugs are on me and my family. I had been paying for my dialysis from 2011 till 2017 when I got a sponsor (R.9, Female, 54 years)

## Physical

### Physical Limitation

This theme of physical limitation was described in four descending subthemes as being general symptoms, food and fluids restrictions, loss of job and change in the way of life.

### General Symptoms

Some participants were aware of general symptoms after dialysis like 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. They get fatigued, especially after doing the 6 hourly sessions. This happens more often when the participants had skipped dialysis and when the toxins are very high. When this happened, the participants usually need to rest after the treatment before they could go home. As one participant said

I can fail to move after (dialysis), even feeling too hot, so I just wake up like the following day, that is when I can start becoming okay but after the dialysis I am too too weak and the dizziness. (R.5, Female, 27 years)

### Food and Fluid Restriction

Some participants observed that they had lost weight because of food restriction, were unable to eat what they liked and expected to eat what they did not like. They could eat posho, rice, cassava, yams, chicken, fish, g/nuts, fresh beans, fresh cow peas, apple juice and apple. They were not supposed to eat beef, and this was difficult. It was much more expensive to buy fish (20,000 UGX) and chicken, and especially a problem since the food bought had to be for the entire family. They needed any extra money to meet hospital cost. As expressed by one participant

When you stay with people who are normal, they cook food which is not the one you are supposed to take and you are forced to take it or sometimes they tell you at home, you remove what you don't want.... (R.4, Male, 21 years)

### Loss of Job

The participants noted frequent weakness when on dialysis and this affected ability of work. Some participants expressed that they could no longer work because of weakness, and also they could not afford to miss two days of dialysis because they had to work. As one participant said

As for now I feel am dropping compared to before, 5 years ago I would leave here (dialysis machine) and go to work but now I can't work I lost my job. (R.9, Female, 54 years)

### Change in the Way of Life

Participants were frustrated by the change in their way of life. They are not able to move freely and once used to fellowship with others they now pray alone. One participant said he used to attend sports event like soccer but now he is no longer able. Participants are no longer able to move as freely as they did. Sometimes participants become too weak to do the usual housework of washing clothes, mopping and cooking. They are angry and irritated that others have to do for them what they used to do. As one participant mentioned

...everything has changed, it has changed, the way I used to live, the way I used to do my things, to do my own house work but now I have to get someone to help me, to assist me, I used to work but I can't. (R.8, Female, 25 years)



## Psychosocial Emotional Distress

This theme of emotional distress was described in six descending subthemes as being worried, fear of dying, feeling of loneliness, loss of friends, feeling of hopelessness and uncertainty.

### Worried

This subtheme emerged from the category as the most common concern these patients undergo. They expressed that they feel like their minds were not within themselves because of the disease. Being dependent on dialysis means frequent trips to the hospital and the participants worried about the transport. They also worried about missing appointments, how to live with the disease and when their life will end. Some participants expressed that they began to worry immediately they were suspected to have kidney disease. They were asking themselves how they were going to deal with it because they had heard that kidney disease had no cure except for a kidney transplant. They knew it was not easy to find a matching donor and very expensive as it involved travelling to India. It is not just a matter of getting a matching donor it also involves court proceedings. They also worried about the cause and if it would also be a problem for their family.

As one participant said

...up to now they have never told me any real cause of my kidney damage even in my family it's only me nobody else has ever suffered from this kind of disease out of the whole family. (R.4, Male, 21 years)

### Fear of Dying

Participants felt that they could die at any time. They were especially aware that if they skipped dialysis for whatever reason they might die. One participant also reported that she has seen those who failed to buy warfarin and other drugs hence could not continue with dialysis and they died.

As one participant said

What if my son fails to meet the cost in future? Then you feel in case he fails that is a sure deal I am going to pack (meaning to die) because we have seen cases where people have failed to get warfarin, what and what have you and they cannot continue with treatment and you hear they are dead. (R.2, Female, 60 years)

### Feeling of Loneliness

Feeling of loneliness made participants frustrated. They expressed their loneliness as being away from people especially family members. For example, a participant had to travel to Kampala for treatment away from his family. One participant stayed with his brother who had to go to work during the day and sometimes at night, leaving him alone in the house. This was reported by one participant

I stay in Bukoto alone without anybody, I eat in a restaurant, I call people to come and wash for me clothes (R.6, Male, 36 years).

### Loss of Friends

Several participants have lost friends because they are no longer able to visit or socialize with them at clubs or restaurants. They said that life only revolved around home and hospital. As mentioned by one participant

...I am cut off from my peers. We had a drinking club though I was not drinking alcohol but I was a member of that club, I could come and they scoff at me. They say the man of tea has come, get a flask full give it to him, give him meat, listen to me and this is the truth, give goat's meat a kilo, he doesn't like to take alcohol with us, give that to him to eat. They pay, you would find they have already paid prospectively; you will come for four months when your food is already paid in advance... (R.1, Male, 54 years).

## Feeling of Hopelessness

The participants expressed feeling of hopelessness because they are not able to attend to other life goals like education as reported by one participant

Right now I am just at home because disease stopped everything, I should have been at school but now I am impaired I cannot go back to school as I have to attend to my treatment. (R.4, Male, 21 years)

## Uncertainty

Participant feels uncertain about the future. They feel that they do not have a future, their future is no more. They cannot predict what will happen to their lives tomorrow. This is because there is no option for treatment and this traumatizes a lot as expressed by one participant

You are living but you don't know tomorrow, you move but you are not sure of your life. (R.2, Female, 60 years).

## Adaptation

This theme of adaptation was described in 5 descending subthemes as: Having a positive attitude towards the condition, simply accepting medical advice, reshaping their daily life, postpones dialysis to take herbal medicine, and spirituality.

### Having a Positive Attitude Towards the Condition

This subtheme emerged from the categories as the most common way these patients used in adapting to hemodialysis. Participants have accepted that they are sick and they forego some other things because of their lives. This is because kidney disease does not cure in a day. Some of them have adapted to staying in Kampala where they can easily access treatment instead of staying in the villages. As stated by one participant

...so when they send you for dialysis then you have to relax and you have to get used to, just make it as part of you, like you should not see it as a very big big burden. (R.8 Female, 25 years).

### Simply Accepting Medical Advice

At first, some participants had gone into a state of denial and had refused dialysis treatment until when they were explained to how dialysis works. Hence, they started picking the idea and eventually accepted it. As one participant said

When I was first diagnosed I accepted it for example when you go to the hospital and they say you have malaria will you say no I do not have malaria, no you cannot say that, you will accept you know...., and go for treatment, so I accepted when I was diagnosed. (R.6, Male, 36 years)

### Reshaping Their Daily Life

Participants realized that when on dialysis, their daily lives have to change. This involves relocating the place of residence to where hemodialysis services can be accessed; restricting self on what one eats, avoiding drinking alcohol and many others. As mentioned by one participant

I have adapted to now staying in Kampala, I am a village boy, every two weeks I would be home but now, like now since corona started I have not been home. Home in terms of home I mean the village, Fort portal I was always there and of course I have adapted to..., I am now getting adapted to Kampala mmh....?. I do not like it but I have to be there anyway because life is important, I think now..., I am thinking even of changing business, I may not teach anymore, I want to do business because, my girl is here she can count the money, I start a business....yah (R.1, Male, 54 years)

## Postpones Dialysis to Take Herbal Medicine

Participants expressed that in their villages they always do encourage them to take herbal medicine. They bring the herbal medicine in bottles including the photos of those whom they claim to have been healed from herbal medicines and they ask them to buy though sometimes they refuse to buy. As stated by one participant

People have advised me on use of herbal drugs, here you cannot miss them, they say if you get a good herbalist, he will give you good herbal medicine and it will cure the kidney disease but then one time I was talking to my dialysis doctor after doing some test he was suspecting kidney disease then he told me you are not so bad may be you have not used these herbal medicine then I realized that these herbal medicines are not good, first of all they have not been tested, so you get advise even on dialysis itself. Somebody came bringing her husband and showed me an herbalist who can give me medicine in phases (R.2, Female, 60 years)

## Spirituality

Participants stated that they leave everything to God because at times they do not have the money but God does it for them. They are believers, they pray and prayers have kept them. As revealed by one participant

..... to me the driving factor is I am a Christian, not only a Christian but you have seen I am SDA, the church has built me to that capacity that I know.....after all when I die, I will see Jesus....(R.1 Male, 54 years)

## Discussion

### Hemodialysis Prolongs Survival

In this study, patients realized that with dialysis life can be prolonged. It cannot heal them of the kidney problems that they have unless kidney transplantation is done. Similarly, in another study, it was revealed that haemodialysis treatment prolongs the life of patients with chronic renal failure disease who must tolerate many physical, emotional, social and economic difficulties.<sup>22</sup>

In a study on lived experiences of patients undergoing haemodialysis, three themes were realized ie acceptance, emotional distress and dependence on haemodialysis where patients undergoing haemodialysis felt that life without haemodialysis is lifeless, they depended on haemodialysis for their living which brought hope of living, felt haemodialysis is a part of their life for surviving (Shah and Chithra, 2017). This could be because chronic kidney disease has no treatment, therefore participants considered haemodialysis as the only way of survival.

It was found in the current study that while haemodialysis therapy has been said to prolong survival, the action of haemodialysis therapy has complications that cause symptoms. This concurs with a study which revealed that haemodialysis prolongs the life of patients with chronic renal failure, but haemodialysis complications always cause these patients to suffer.<sup>23</sup>

### Hemodialysis is Indispensable

In the current study, participants expressed that dialysis is life already because when a patient starts dialysis the symptoms of Chronic Kidney Disease (CKD) subside and they get great improvement. This is in agreement with a study which revealed that most of the participants have positive regard for dialysis, knowing that they feel much better after starting the dialysis.<sup>24</sup>

Furthermore, in this study, the participants noted that being on dialysis is not condemnation and a patient with CKD should be on dialysis in order to survive and even when they die, they will die a satisfied man. In a study regarding the adherence to treatment of haemodialysis patients, it was found that participants regarded haemodialysis as what kept them alive and so they came for it. A number of those who found it hard also acknowledged that it kept them alive.<sup>25</sup>

It was also noted in the present study that participants revealed that there can be symptoms like weakness as a result of haemodialysis but these symptoms always last for a short time and the patient will feel strong again. Therefore, the only way a patient can feel good is to do dialysis. This is consistent with a study which found that since HD is

a lifesaving treatment, the impact on symptom burden may be overlooked.<sup>26</sup> Despite having experienced some negative aspects of HD, the patients in this study recognised the importance of maintaining a positive outlook about their circumstances, acknowledging that HD has provided them with a lifeline. This could be because participants had no better option for treatment of their kidney disease since transplant is expensive and not easily accessible.

In a study conducted in three New York State haemodialysis centres in Brooklyn, the Bronx, and Suffolk County, numerous themes emerged from the data that clearly spoke to the lived experiences. The experiences included challenge of fluid control, and another theme included difficulty, frustration, pain and stress, where two-thirds of the patients expressed these themes in their responses. Most patients realized that haemodialysis is something that must be done, no matter how frustrating or difficult it is.<sup>25</sup> This finding is similar to this study whereby participants looked at haemodialysis as lifesaving and must be done to save life.

Lin et al<sup>27</sup> in their study revealed that participants honestly believe that the machine is the controlling influence in their lives. Without the dialysis machine, people are unable to relieve their suffering physically but, at the same time, they suspect it may have continued their emotional suffering. The participants were confined to a renal world to the extent that they felt powerless in the direction of their lives. Their only way of dealing with the situation was to modify their perceptions and life values. Faced with the problem of the treatment, their means to physical life but a barrier to a meaningful future, they altered their perspective by living in the present, labouring to make the most of each moment. These results were slightly different from those of the current study which found that people receiving HD therapy felt good and accepted it as part of life, although they felt their lives were “tied down”. This is probably because participants considered the benefits of dialysis to outweigh the challenges.

## Family Financial Support

Family financial support is one of the important themes that emerged from the study participants.

In the present study participants expressed that family is very important to support the patients on dialysis and the importance of dialysis should be explained to the family. Most of them got support from their family in terms of finances since they can no longer do activities that earn them salary. The family members that were found to be of help to these participants were their spouses, children, parents and siblings. In the same way, in a study conducted in Singapore, family support stood out as an important tool in adapting to life with End-Stage Renal Disease (ESRD). It emerged as patients' primary means of coping with the day-to-day challenges of the disease and treatment. Support from family especially children commonly included financial, practical and emotional support.<sup>28</sup>

In another study conducted in Singapore, it was found that family support was identified to be the core support system that encourages positive adherence behaviours like dietary and fluid recommendations.<sup>29</sup> This could be because the family members often play an important role in managing chronic illnesses and a family approach may produce more effective, long-term benefits for the patients.

Rohini and Ezhilarasu<sup>30</sup> in their study on lived experience of patients undergoing hemodialysis in quality-of-life perspective reported that there is support and comfort from husband and relatives in long-term hemodialysis treatment and this is in support with the current study. Contrary to this, another study conducted in Iran noted that participants lacked support from their family members, and lack of endorsement from the family can hamper efficient dialysis by creating a negative subject feeling of lack of belonging and acceptance, lack of interest and understanding that there is no support to receive help from when required.<sup>31</sup> This could be because of African traditional culture belief in support of family in times of illnesses.

Another study conducted in Iran, which is in congruence with the present study, found that support from the family was also an important coping resource. Family offered both practical support and emotional comfort.<sup>26</sup>

## Physical Limitation

In the present study, the majority of the participants suffered from physical symptoms due to dialysis. They also expressed their feelings regarding physical impairment. They were not able to carry out activities of daily living due to these symptoms, and they depended on others for even simple activity that they used to do. The findings are consistent with the study conducted in the renal unit of Indira Gandhi Medical College and Hospital, Shimla in India, which found

that 60.4% of the patients suffered from physical symptoms due to dialysis, 10.4% had feelings of physical impairment, physical restrictions, weakness, inactivity, and effects on daily physical activity, and 4.1% had feeling of physical dependency on others.<sup>32</sup>

In this study, the physical symptoms that were experienced by the participants were as follows: dizziness and tiredness especially after the machine and most of them needed a bed rest before going home, fever, weakness, and fatigue mostly after the six hourly sessions, and this rendered them unable to move immediately. This result is similar to a study conducted in the Middle East which found that fatigue is a negative symptom experienced by a large number of patients with end-stage renal disease undergoing haemodialysis and they experienced this fatigue immediately after the dialysis and were not able to carry out daily activities and experienced role limitations and a decrease in strength and physical ability due to their fatigue.<sup>22</sup>

Other symptoms were loss of body colour, loss of weight, back ache, loss of energy, and loss of appetite, menstrual irregularity, muscle and bone cramps, headache and feeling of being uncomfortable. This is supported by a study conducted in Singapore where participants described themes that had a significant impact on their physical health and which significantly affected their activities of daily living and quality of life. These included general symptoms (dyspnoea, dizziness, oedema, nausea and loss of appetite), neuromuscular symptoms (aches, weakness causing mobility difficulties).<sup>28,33</sup> In another study, two themes were identified as interpersonal and intrapersonal impacts and are further divided into mental and physical impacts. Under the physical impacts, participants experienced feeling of tiredness, feeling weak, and back pain.<sup>34</sup> Valsaraj et al<sup>24</sup> in their study also found that haemodialysis causes a variety of symptoms among individuals.

In this study, depending on others for even simple activities that they used to do like mopping made these participants frustrated. This is congruence with a study, which found that physical illness was the most common complaint of those on dialysis and participants become emotionally depressed and pessimistic, which caused them to be inactive in their daily lives.<sup>27</sup>

In this study, participants revealed that kidney disease has greatly diminished their lives because they are restricted on food and other drinks which they used to consume. They further stated that the management of food itself is really very difficult because sometimes they stay with people who are normal and they cook food which they are not supposed to take and they are forced to eat, for example, spiced food and tomatoes. In the same way, Ford-Anderson<sup>25</sup> found in his study that thirteen of the patients reported that restricting fluids was hard. They were always thirsty and felt parched, drained, and deprived. Only 4 patients reported that restricting fluid was not hard, 3 of whom cited the dire consequences of fluid overload. In another study, 90.9% of responses showed feelings of dietary restrictions and compromised as a result of dialysis treatment.<sup>30,32</sup>

Furthermore, participants in this study also asserted that they get affected by food restrictions because what they used to eat they can no longer eat them and those they want them to eat they do not like them. In the same way, in a study conducted in Singapore, it was shown that the imposed dietary restrictions prevailed as an enduring suffering, which intensified the feelings of distress and frustration. Even so, most participants have reportedly been compelled to acknowledge the necessity of the restrictions to avoid potential complications.<sup>29</sup>

## Emotional Distress

This study revealed that patients were feeling distress due to their disease condition. They expressed that life is not easy when on dialysis. They expressed worries, fear of dying, feeling of loneliness, loss of friends, feeling of hopelessness and uncertainty. They were worried that they are going to die anytime. These participants were worried because they do not have answers to their disease. They were also worried about the financial expenses because they did not want to miss the sessions. This was also reported in a study conducted at the renal unit of Indira Gandhi Medical College and hospital, Shimla, which showed that 52.6% of the patients were worried about financial expenses.<sup>32</sup> This could probably be because most of these participants no longer work to earn salary and they find it difficult to meet the cost of payment.

In this study, participants expressed that they were worried about their lives, how they are going to live with the disease, when it will end and that tortures them a lot. They expressed that they started worrying immediately after suspecting them to have kidney disease. They were asking themselves how they were going to go about it because they had already heard that kidney disease has no cure except if one gets a transplant of which it is not even easy to get a donor, above all getting

a matching donor and it is expensive as it involves travelling to India. It is not just a matter of getting a matching donor, it also involves court proceedings. This is similar to a study where participants reported that one of the hardest parts of the treatment process is the multiple unknowns, they do not know how long the treatment will last, whether they will ever be rid of HD and whether they will ever get a transplant. Consequently, they viewed HD as a never-ending process from which they could not escape, which lead to feelings of frustration, resentment and depression.<sup>35</sup>

In a study conducted in Thailand, participants defined the limitations on life in terms of physical, social, and economic aspects that often caused emotional distress and this is not in any case different from the present study.<sup>36</sup>

Uncertainty is a psychological challenge and disease comorbidity for haemodialysis patients.<sup>37</sup> Uncertainty puts the patients in an unknown position for the future. In this study, participants were not sure of tomorrow and not sure of their lives though they are living, this is because there is no option for treatment and this traumatized them a lot and impacted on their mind. This is consistent with a qualitative study conducted in Thailand on the lived experience of patients receiving haemodialysis treatment for End-Stage Renal Disease which found that while all participants reported that their HD therapy was going well, they expressed worry about an unpredictable future.<sup>36</sup>

In this study, participants feel that any time they can perish especially if they fail to meet the cost of dialysis and this brings them a lot of worries. Another study conducted in Iran among the elderly people undergoing haemodialysis revealed that lack of knowledge and fear of death due to uncertainty was important to the participants. The patients see themselves in a limbo between life and death due to lack of information and doubt. Fear of death and the unknown following haemodialysis places the patients in an uncertain position.<sup>30,37</sup>

## Adaptation

In this study, participants adapted to haemodialysis treatment through the following: having a positive attitude towards the condition, simply accepting medical advice, reshaping their daily life, postpone dialysis to take herbal medicine and spirituality.

The participants stated that they are believers and they pray. Prayers have kept their hopes high and God provides for them for instance, sometimes they lack the finances to support their medical bills but they trust in God who provides for them. This is congruence with a study in Iran, which found that the religious aspect, including praying or trust in God, was the most frequently used and helpful coping strategy in HD patients; this is largely related to the prominent position of religious beliefs in the culture and life of Ugandans.<sup>38</sup> This same coping strategy was equally used by participants in Iran where they revealed that when they feel seriously stressful, they go to the mosques and feel calm. They say to themselves that it is an event which may happen for another person. The beliefs and religious affairs make them calm.<sup>39</sup> In this present study, participants accepted their conditions and simply accepted medical advice. They had no other option since ESRD has no cure. This came along with a sense of being dependent on health workers. This is in accordance with a qualitative cross-sectional study which found that participants followed doctors' orders and accepted their condition.<sup>40</sup> In the same way, in Taiwan, some clients responded to HD by simply accepting medical advice and it involves a sense of dependence on health professionals. Participants saw their need to receive dialysis treatment as a fate that they had limited power to fight against. However, a fate reflects no personal responsibility to be taken on dialysis.<sup>27</sup> This is possible because these participants had no any other choice and option than to depend on health care providers. In this study, some participants resorted to using herbal medicine as a result of influence from peers. This was in search for better treatment for their kidney disease. This concurred with a qualitative study in Taiwan which found that some participants suspended dialysis treatment and took herbal medicine for their physical discomfort with the hope that the disease was not progressive enough to warrant HD and some considered dialysis as a treatment of last choice.<sup>27</sup> This is possible because of the peer influence from those who have ever used the herbal medicine.

## Limitations of the Study

The limitation of this study lies in the small sample size and lack of generalizability due to the nature of the selection of qualitative phenomenological design. Though the research design was appropriate to explore the lived experiences of the target population, the sample size ( $n = 9$ ) limited the ability of the experiences to be generalized beyond the participants.

The self-selecting nature of participants could have led to recruitment bias such that only those with strong views about HD participated. This possibly explains why our findings share a high level of similarity with other qualitative studies in the area of HD.



## Conclusions

It was concluded from the findings that the patients undergoing haemodialysis are facing a wide range of problems such as physical and emotional problems during the course of their treatment and think haemodialysis is the only way of survival and these problems need to be addressed. Understanding gained in this study can help nurses to utilize this information in improving the quality of nursing care and guide patients to provide positive reinforcement for their future living.

## Abbreviations

CDC, Centre for Disease Control; CKD, Chronic Kidney Disease; ESRD, End-Stage Renal Disease; FREC, Faculty Research Ethics Committee; HMIS, Health Management Information System; HD, Hemodialysis; HIV, Human Immunodeficiency Virus; KDOQI, Kidney Disease Outcomes Quality Initiative; KNRH, Kiruddu National Referral Hospital; MUST, Mbarara University of Science and Technology; MNRH, Mulago National Referral Hospital; PMP, Patients Per Million of General Population; REC, Research Ethics Committee; USRDS, United States Renal Data System.

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## Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising, or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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## Disclosure

The authors report no conflicts of interest in this work.

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