



Lived experiences of patients undergoing maintenance haemodialysis at the Benue State University Teaching Hospital, Makurdi: A descriptive phenomenological study

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Abstract

Introduction: Despite its global effectiveness in the treatment of end stage renal diseases, haemodialysis is associated with a lot of complications which affect patients' quality of life, particularly, in the low-income regions of the world, such as Nigeria.

Objectives: The objectives of this study are to describe the physical, social, economic, and psychological lived experiences of patients undergoing maintenance haemodialysis at the Benue State University Teaching Hospital, Makurdi.

Methods: Qualitative descriptive phenomenological design was adopted to purposively study consented 20 participants undergoing maintenance haemodialysis at the Benue State University Teaching Hospital Makurdi, Nigeria, using a semi-structured questionnaire and audiotaping. The collected data was coded, analyzed into themes and sub-themes with the help of N Vivo software 10.

Results: Following the study objectives, 4 overarching themes and 13 sub-themes were revealed. Under physical lived experiences, participants experienced various types of physical discomfort and hypertension; for social lived experiences, participants reported social detachment, social life dependent and social limitations. Economic lived experiences included financial difficulties, job loss and lack of financial subsidy to cope with haemodialysis treatment bills while, for psychological lived experiences, the study revealed psychological torments, living under uncertainty and living a prepared life.

Conclusion: Lived experiences of haemodialysis patients are the same as signs and symptoms. Therefore, renal nurses should identify these signs and symptoms early enough for timely intervention in order to ameliorate patients' suffering thereby, improving their quality of life.

Keywords: Descriptive, experiences, haemodialysis, lived, patients, phenomenological, qualitative, quality of life

Introduction

Haemodialysis (HD) is an effective workable treatment modality for chronic kidney disease (CKD) and end stage renal disease (ESRD) globally, and in particular, the sub-Saharan where it predominates^[1]. Frequent unavailability of consumables, its higher costs; very high incidence of peritonitis associated with peritoneal dialysis; scarcity of skills, equipment, contraindication and scarcity of donors for kidney transplantation has made the application of this emerging health technology predominant^[2].

Before the introduction of haemodialysis therapy, diagnosis with end stage renal disease was a death sentence, however, in 1943 when the haemodialysis treatment was introduced, the medical technology led to a remarkable improvement in the survival of these patients with better care^[3]. Despite the benefits of haemodialysis treatment for end stage renal disease patients, it is associated with some severe complications which negatively affect the quality of life (QoL) particularly, in the low-income regions^[4].

Statement of problem

Haemodialysis lengthens the life of end stage renal disease patients, but this is not equal to good quality of life^[5]. Available relevant literatures have shown that, patients on maintenance haemodialysis continue to suffer from physical weakness, physical pain, intradialytic high and low blood pressures, insomnia, catastrophic spending, frequent admission and readmissions into intensive care and emergency units, comorbidities, loss of job, unemployment,

restricted life style, social detachment, dependence on caregivers, disruption of marital, family, and other social life, depression that severely compromised their standard of life and shortened life span etc.^[6]. These ugly experiences are magnified particularly, in the low and middle-income regions of the world such as Nigeria, where there is extreme poverty with rising cases of end stage renal diseases, partial medical subsidy packages, lack of other affordable treatment modalities, haemodialysis facilities, skills and where prevention of diseases is difficult to achieve^[7].

Objectives

Specifically, this study intends to describe the physical, social, economic and psychological lived experiences of patients undergoing maintenance haemodialysis at the Benue State University Teaching Hospital, Makurdi using a descriptive phenomenological approach.

Significance of the study

Nurses: Findings from this study will help nephrology nurses to manage unpleasant symptoms of both the chronic kidney disease and its treatment to achieve quality care that is sufficient enough to meet the health needs of the haemodialysis patients.

The study findings will also help nurses eliminate nursing actions that do not help to achieve the desired results; identify and implement those practices that can change outcomes.

Nurse researchers will find the work as a pool of information for citation.

Findings from the study will enhance collaboration among nurses, nurse managers and other professional healthcare cadres such as psychologists, psychiatrists, dieticians, laboratory scientists, pharmacist, nephrologist, physicians etc. to render quality care to haemodialysis patients.

The society: The study findings will serve as evidence of production of new knowledge that will inform the society on how to organize themselves around healthy lifestyle that will prevent kidney injury and achieve health goals that will make them to be productive in life, and achieve quality of life and longevity.

Health policy makers: Findings from this study will enable policy makers to design healthy health policies that will address issues of public health concerns that will benefit particularly the poor masses by providing health insurance packages for haemodialysis patients and other patients with chronic diseases and narrow the health inequity gap^[8].

Health research funding agencies: The findings of this study will serve as empirical evidence and scientific valid information for the benefit of the research funding agencies that will be used to put to real-world use and to exert influences on health policy makers and health service delivery institutions to advance knowledge and generate new ideas which will lead to a healthy society, productive economy and sustainability.

Institutional Repository (IR): To the University of Nigeria Nsukka, as the work is submitted on the Institutional Repository (IR), it will form part of the condensed tip of the educational contributions of past and present academia, broadening to include scholarly enterprise, literary achievements, hypothetical reasoning and an array of intellectual gifts from the University of Nigeria to anyone whose search for answers and solutions brings them to this doorstep to serve users, staff, students and researchers from the south-East Zone of Nigeria in particular and other researchers globally.

Conceptual review

Haemodialysis

Haemodialysis is the most common form of kidney replacement therapy globally today with the prevalence of 69% among the renal replacement therapies^[9]. It is treatment for chronic kidney disease patients particularly, end stage renal diseases, where an artificial kidney called haemodialyzer, is used to remove waste products, extra chemicals and fluid in the blood^[10]. The process takes place in an artificial blood circuit, which begins at the patient's vascular access as blood is pumped through soft tubes to a dialysis machine where it goes into the dialyzer to filter it, after which it is returned to the patient's bloodstream through the artificial venous bloodlines^[11]. Haemodialysis has several benefits as it can help to wash out the uraemic toxins, prevent inter-dialytic weight gain thus, reducing hypotension episodes; less cramping and no "washout" feeling. Other benefit of haemodialysis includes but not limited to better blood pressure control, less antihypertensive drugs, improvement in anaemia, reduction in the use of erythropoietin dose and iron supplements, reduction in left ventricular mass index. Haemodialysis can also bring about improvement in mineral metabolism and

reduction in phosphorus binders, improvement in nutritional status, reduction in hospitalization rates and costs, increased cumulative survival rate, thus enhancing quality of life^[11].

Quality of life

Quality of life is a broad multidimensional concept that has meaning for nearly everyone, every academic discipline, individuals and groups. The term quality of life can refer both to the experience and the living conditions in which individuals find themselves making it highly subjective. Whereas one person may define quality of life according to wealth or satisfaction with life, another person may define it in terms of capabilities. A disabled person may report a high quality of life, whereas a healthy person who recently lost a job may report a low quality of life. (Jenkinson, 2023^[12]). The concept of quality of life has undergone some evolutions such that, when applied to health-related matters (health related quality of life [HRQoL], particularly in relation to haemodialysis patients, it embraces domains related to physical, mental, economic, emotional and social functioning^[13].

Haemodialysis patients have a double life experience to cope with: disease related stress and haemodialysis unpleasant symptoms and people in Nigeria living with end stage renal diseases describe it as death sentence^[14]

Theoretical review

Theory of unpleasant symptoms (TOUS): Audrey Gift and Linda Pugh authored the theory in 1995 and revised it in 1997^[15]. TOUS is a middle-range theory in healthcare services that seeks to improve understanding of the symptom experience in various contexts (in this study, haemodialysis treatment) and to provide useful information for designing effective means to prevent, ameliorate, or manage unpleasant symptoms and their negative effects exerted on the patient^[16].

According to the theory, multiple symptoms may occur simultaneously from an illness or treatment (in this study, hemodialysis treatment) which interact with each other and could be multiplicative^[15].

Constructs of theory of unpleasant symptoms: The TOUS consists of three major constructs: symptom experience (attributes), influencing factors (antecedents), and consequences (performance) and four minor constructs: suffering, quality, intensity, duration or time^[17].

The symptom experience: Embraces subjective and objective indicators of health threats. It points out changes by clients in the expected functioning of the human body, generally experienced as unpleasant as the patient undergoes maintenance haemodialysis which is supposed to change the natural course of the underlying disease, in this study, the kidney failure^[18]. In order words, instead of the patient experiencing healing, the treatment itself rather produces various problems and complications^[19]. Examples of symptom experience may include chronic headache, backache, nausea, vomiting, hypotension, hypertension, chills, and infections and so on.

The influencing factors: Reflect factors that worsen the unpleasant symptoms experienced by the patients undergoing maintenance haemodialysis treatment which may include physiological, situational and the psychological factors^[17].

The consequences of the symptoms experienced (performance): Reflects the effect of symptoms experienced on the functional and cognitive status of the haemodialysis patients [17]. In other words, it is the impairment relating to functions and intellectual activities as a result or effect of the unwelcome or unpleasant symptoms experienced and complications caused by the haemodialysis treatment of the patient with chronic kidney disease [18].

The minor constructs

Suffering: refers to the degree of discomfort of the individual in relation to the unpleasant symptom or group of symptoms experience [18].

Quality: represents the variation of the unpleasant symptoms experienced or the way they are manifested [19].

Intensity: is related to the strength or severity of the unpleasant symptoms experienced which is quantifiable or can be described as mild, moderate, severe, pounding, sharp etc. Intensity of unpleasant symptoms experienced by hemodialysis patients is the most discussed dimension in clinical assessment and research [16].

Duration: embraces the frequency and length of time of unpleasant symptom (s) experience which may occur in isolation or in combination with several other symptoms. For instance, intradialytic hypertension may occur in combination with headache, nausea and vomiting lasting for a period of 30 minutes or to any length of time with or without nursing and medical intervention [18].

Empirical review

Jarial and George [20] conducted a study on the ‘Lived Experiences of Patients Undergoing Haemodialysis’ in India with the aim of exploring their lived experiences and to generate data for improving quality of nursing care. The study utilized a qualitative approach with phenomenological design. Data was purposively collected from eight participants utilizing semi-structured interview and audio tape recording. Colaizzi’s procedural steps were used to process the data. The result of the study showed that, dialysis had a negative physical, family, societal, psychological and emotional impact, perception towards health care service, dietary restrictions, communication aspect, religious beliefs, economic and job impact. The study concluded that, haemodialysis patients need extreme positive support networks from family, health care systems and society so that feelings of isolation, hopelessness and depression can be avoided.

Ekuma [14] conducted a study on “No Money, No Treatment, No Life: The Lived Experiences of Haemodialysis Patients in Nigeria” to explore the experiences of chronic kidney disease patients undergoing dialysis in healthcare systems with unequal access to treatment. Cross-sectional method was used, while purposive sampling was adopted to collect data from 17 participants through narrative interview means. Data collected were analyzed thematically into nine [9] as follows: uncertainty was associated with possible prognosis of the disease condition and the treatment outcomes; meaning of illness and the life. Body image, pains and weakness in their physical bodies as they commenced haemodialysis treatment were revealed. Loss or reduction of freedom to carry out activities of daily living independently,

pruritus, restless leg, allergy to paper tape, symptoms which were often not considered important by their healthcare providers. The study findings also revealed that, only those who had money to access haemodialysis live longer, but those without it died early. Even those who lived, their survival came at a big price when their friends, colleagues, family and in some cases, the village would have to sell their assets to fund the short-term haemodialysis treatment. This however resulted to poverty to the patient, friends, the family and the society. Decisions to attend hemodialysis or adhere to treatment regimen were influenced by cultural practices/societal norms, costs issues, geographical barrier, family needs and religion. Beside poverty, lack of accurate information on conservative management forced patients to make decisions to commence haemodialysis, resulting in early death. The study concluded that, healthcare practitioners need to provide accurate information on conservative management to enable patients to make informed choices over their lives. They should be discouraged from selling all they have to pay for treatment, stripping themselves and their families of meagre resources, for very little gain, and health policy should support funded hemodialysis programmes.

Beng *et al* [5] conducted a qualitative study on “The experiences of suffering of end-stage renal failure (ESRF) patients in Malaysia: a thematic analysis”. Using a semi-structured interviews to explore the experiences of 19 suffering ESRF patients on maintenance dialysis in Malaysia, the data collected was thematically analyzed through NVIVO9 software. Results revealed physical, social and psychological sufferings as themes and subthemes. In conclusion, the information gathered was used to render best renal palliative care.

A recent qualitative descriptive study by Gebrie *et al* [21] on “Patients’ experience of undergoing maintenance haemodialysis. An interview study from Ethiopia’ were analyzed using reflexive thematic analysis after data was collected from 19 haemodialysis patients. The analysis showed 5 themes and subthemes stretching from being too weak, stigmatized, financial constraints to lack of access to care. The study concluded that, haemodialysis patients generally had a considerably negative narrative. The study recommended that, different health teams should focus on meeting the physical, emotional, and social needs of haemodialysis patients, not forgetting to involve the family members.

Khame [22] carried out a descriptive study on the “Social-Economic Life Experiences of Patients on Kidney Haemodialysis in Botswana” with the objective to explore and describe the social-economic life experiences of patients undergoing kidney haemodialysis at a public healthcare facility in a developing country, Botswana. Adopting a qualitative, explorative, descriptive and contextual phenomenological design, a non-probability purposive sampling method was used to obtain data from 10 participants through in-depth, face-to face, semi-structured interviews and audiotaping. Data were analyzed thematically using Creswell’s six-step model. The result revealed that, haemodialysis patients appreciated the treatment, but experienced challenges related to physical and psychosocial factors; transport challenges and distance from the haemodialysis centre; economic difficulties and altered family responsibility.

Material and Method

Study design: The study employed a qualitative descriptive design of phenomenological nature. Qualitative research describes diverse research approaches that seek to understand human experiences, perceptions, beliefs, intentions, opinions, motivation, and behaviours by means of exploration [23]. Gabrie *et al* [21] used qualitative descriptive design to study patients' experience undergoing maintenance hemodialysis, from Ethiopia. The intention behind the adoption of the descriptive qualitative research approach in this study was premised on the fact that, data would be collected from the haemodialysis participants with the view of unveiling the needed information, and describing their lived experiences.

Study setting: The study was carried out at the Haemodialysis Unit of the Benue University Teaching Hospital (BSUTH), Makurdi, Benue State, Nigeria. It is a 300 bedded tertiary healthcare institution with 23 clinical units and 19 administrative departments. It was commissioned on the 9th March, 2012 and became operational on the 26th March, 2012 (BSUTH magazine, 2016). The haemodialysis unit has five (5) haemodialysis machines that have been functional for the past ten (10) years. On average the facility performs haemodialysis on 460 patients yearly (haemodialysis patients' log book, 2012-2022).

Study population/participants: The population for the study included all patients undergoing haemodialysis at the haemodialysis unit of BSUTH, Makurdi during the time of this study.

Sampling: 20 patients comprising 15 males and 5 females were purposively recruited for the study.

Inclusion criteria: Patients diagnosed with chronic kidney diseases or end stage renal diseases; undergoing maintenance haemodialysis at least 3 months at the haemodialysis unit, BSUTH, Makurdi at the time of the study; with no mental or cognitive impairment; has the ability to give informed consent or conscious; willingness and availability to participate.

Instrument for data collection: A self-developed instrument for data collection comprising a brief questionnaire and semi-structured interview guide with open-ended, face-to-face or one-on-one and computer-assisted (audiotaping) was adopted. The brief questionnaire consisted of participants' socio-demographic data while the semi-structured interview guide had questions that elicited information on physical, social, economic and psychological lived experiences of study participants who were undergoing maintenance haemodialysis. Other tools used for data collection were the principal researcher and 4 trained research assistants.

Validity of the instrument: The face and content validity of the instrument was established by giving a copy of the drafted semi-structured interview to the supervisor and other experts in the Department of Nursing Sciences, Faculty of Health Sciences and Technology, University of Nigeria,

Enugu Campus (UNEC). They critically examined the instruments and made all the necessary corrections to ascertain that it covers the objectives of the study.

Enhancing rigor in qualitative research: Rigor simply means trustworthiness of qualitative research results by adopting appropriate methods that minimize the bias inherent in qualitative studies thus helping readers to trust the research and the researcher [25]. In establishing trustworthiness, a stringent criterion in qualitative research, known as credibility, dependability, conformability and transferability was adopted as outlined by Lincoln and Guba [25].

Ethical consideration: A letter of introduction collected from the Head, Department of Nursing Sciences, Faculty of Health Sciences and Technology, University of Nigeria, Enugu Campus (UNEC), the research proposal comprising chapters one to three and a copy of the semi-structured guide for interview was attached to a written application and submitted to the research and ethical committee of Benue State University Teaching Hospital, (BSUTH) on the 21st February, 2023. Approval with reference number: HREC NO: BSUTH/MKD/HREC/2023/017 was given on the 25th April, 2023.

Informed consent was obtained from the participants after a brief but concise information was given to their understanding and satisfaction on the purpose of the study. They were also informed that, no data will be traced to their identity as their names were replaced by codes (pseudonym). Their social contact were also protected from unauthorized persons. All tapes used for data collection were destroyed after transcription were completed, edited and sent back to some of the participants for member checking.

Procedure for data collection: The total period of time for data collection took 5 months (26/4/2023-31/11/2023) due to attrition of participants and frequent breakdown of haemodialysis machines. Although, data saturation was reached on the 14th participant, all prospective participants were interviewed in order to make for more robustness, thus, ensuring that, no new information was not missed out. Data collection was audiotaped by the four (4) trained research assistants. The interview sessions took place when the patients were on the haemodialysis machine during the last 35 minutes of the haemodialysis procedure during which time, most patients became more stable and relaxed than the initial first hour when their critical symptoms had not been relieved. For the haemodialysis patients on admission, their interview sessions took place at their bedside between the hours of 6 pm and 7 pm, when visitors were through from visiting the patients and the wards were at minimal activities to reduce interference with routine patients' care. Each participant's bed was screened off during the entire period of the interview to minimize interference from environmental distraction, to secure privacy, and confidentiality as well as have an effective audio recording. The interview was carried out in English with the use of interview guide.

Method of data analysis: The returned copies of the questionnaire on socio- demographic data of participants were properly crosschecked for completeness of information, organized into frequencies and percentages with the use of statistical software package for social sciences (SPSS) version 20.0 and presented using tables for descriptive purposes.

For the qualitative data, the audiotaped data describing all participants’ lived experiences were played and listened to several times to gain a sense of the whole. Participants’ names were coded using alphabets in order to maintain anonymity. The analysis continued throughout the period of data collection. The interpretation of the text was moved back and forth across Husserl's method of analysis which consists of four (4) steps namely; bracketing, intuiting, analyzing and describing (25). NVivo 10 software was used to simplify the whole process into meaningful themes and sub-themes.

Results

Table 1: Socio-demographic characteristics of the participants (N=20)

Variable	Category	Number	Percentage	Mean	Standard Deviation
Gender	Male	15	75	53	9.08
	Female	5	25		
Age	31-40	1	5		
	41-50	7	35		
	51-60	9	45		
	61-70	2	10		
	71-80	1	5		
Marital status	Single	1	5		
	Married	18	90		
	widow	1	5		
Religion	Christianity	17	85		
	Islam	3	15		
Educational Qualification	Primary	6	30		
	Secondary	10	50		
	Tertiary	4	20		
Occupation	Farmer	3	15		
	Business	6	30		
	civil servant	7	35		
	Others	4	20		

Of the 20 participants, 5 were females; mean age of 53 years ranging from 23 to 78 with the standard deviation of 9.08. Eighteen (18) participants were married while of the remaining 2, one was a widow while the other participant was single. Majority of the participants were Christians (17), while the rest were Muslims (3). Their educational status included primary (6), secondary (10) and tertiary (4). The participants’ occupation was farming (15), business (30) civil servants (35) and 4 survived by doing various things for living.

Physical lived experiences of patients undergoing maintenance haemodialysis at the Benue State University Teaching Hospital, Makurdi.

Table 2: Theme 1 and Subthemes

S/n	Theme 1	Sub-themes
1	Physical Lived Experiences	1. Physical pain
		2. Nausea/vomiting
		3. Physical Fatigue

Theme 1: Physical Lived Experiences. This refers to those lived physical health related issues that a patient experiences as a result of undergoing hemodialysis treatment.

Sub-theme 1: Physical pain. Undergoing maintenance hemodialysis was a necessity for patients diagnosed with chronic kidney disease since the treatment could improve their quality of life. However, this treatment was a new painful experience altogether as seen through the extracts from the verbal recording and transcriptions of their statements.

“My blood lines are difficult to get, any time I get here they have to “chuk” (pierce) me for blood test” - participants A, C
 “Can’t they just give me tablet to take instead of giving me injection on my groins?” Participants P, T
 “I always have headache” (participants I, J, L, M, S)

Sub-Theme 2: Nausea and Vomiting-nausea refers to feeling of sickness with an inclination to vomit while vomiting is the forceful ejection of gastric content through the mouth. Nausea and vomiting are one of the most prevalent symptoms in all hemodialysis patients [26]. Most participants spoke about experiencing nausea and vomiting in various ways:

“Even without eating unpleasant food, I feel like vomiting,” participant A.
 “As soon as nurse put me on the machine, I start to throw up”. Participant D.
 “I pity the nurse that day, I bathed her with my vomitus”, participant M
 “I always vomit especially during dialysis” participant T

Sub-Theme 2: Physical fatigue- refers to a situation where a patient on maintenance haemodialysis treatment suffers from decreased levels of physical activity, low functional capability, and general muscle weakness, which results in a general feeling of tiredness (2027).

“This machine treatment is necessary and good, but it drains all my energy- Participant T;
 “Am always not myself after coming down from that machine, and as a driver, I can’t drive long distances again” Participants D;

Sub-Theme 4: Hypertension is commonly associated with chronic kidney disease patients undergoing hemodialysis (28). More than half of the study participants reported suffering from hypertension as seen below from some of their extracted statements:

“The doctor told me that, I have to be taking my drugs (anti-hypertensive) daily for my symptoms to improve” – participant A
 “Sometime doctors and nurses would give me injection to crash down my B. P”- participant M”.
 “I remembered the nurses could not continue with my dialysis the other time, because of high blood pressure”- participant O;
 “Hmm, last time after dialysis, I nearly died, they have to give me admission to control my B. P”-participant R.

Social lived experiences among patients undergoing maintenance haemodialysis at the Benue State University Teaching Hospital, Makurdi.

Table 3: Theme 2 and Subthemes

S/n	Theme 2	Sub-themes
2	Social Lived Experiences	1. Social detachment
		2. Social lived dependence
		3. Social lived limitation

Sub-Theme 5: Social Detachment. Although haemodialysis gives life again to the patients, almost all the participants expressed their negative view about it as follows:

“Machine treatment takes very long hours and boring.... I go home very tired only to sleep and wake up the following morning,” participant A.
 “I used to move together with people, as I wanted. I had good relationship with many family members and neighbours. Now, I feel that, my neighbours think I only come around looking for financial help for my treatment. So now I don’t go anywhere again”-participant Q;
 ”I don’t like moving out after dialysis to avoid neighbors asking me, what’s hanging on your neck (jugular catheter for access)”-participant R.

Sub-Theme 6: Social lived dependence: Away from social detachment, participants also experienced social lived dependence as expressed by some of them:

“They (doctors & nurses) are so nice to me; I depend on them for my treatment”- participant B;
 “They instructed me to be bringing somebody with me, but I don’t have anybody, that attendant is always wheeling me on the chair, helping me to collect my blood from the blood bank”- participant D;

Sub-Theme 7: Social lived limitation- In this sub-theme, participants discussed how their social life, particularly their family life are impacted by their haemodialysis treatment. Find below some of their claims:

"I don't even have time for my husband anymore... I have to go there for dialysis always...after that, I don't have any energy left for him again"- Participant F
 “I can’t remember the last time when I laid in bed with my wife... I lost all interest...my thing (manhood) doesn’t stand again”-Participant K.
 “I told my husband to marry another woman, if he wouldn’t mind. What kind of wife that cannot cook or satisfy her husband in bed? Am finished (weeping)”-Participant O.
 “I am being burdened about my role in my family. Am no longer the bread winner, I can’t give money for soup, I can’t pay my children’s school fees, I can’t bring out the money to pay our house rent, this thing (haemodialysis treatment) has led me to poverty”-participant M.

As clearly seen above, the majority of the participants were unable to fulfill their marital or family roles, and they believed that their relationship is suffering as a result.

Economic lived experiences of patients undergoing maintenance haemodialysis at the Benue State University Teaching Hospital, Makurdi.

Table 4: Theme 3 and Sub-Themes

S/n	Theme 3	Sub-themes
3	Economic lived experience	Financial difficulties
		loss of Job
		Lack of medical subsidy package

Sub-Theme 8: Financial difficulties- all the participants expressed various worrisome concern over financial difficulties about funding the haemodialysis treatment and other cost associated with it. For instance, transportation, medical laboratory investigation and blood transfusion costs being of a great burden. Find below are some of their expressions:

“They (nurses) told me that, good dialysis is when am doing it 3 times a week. But as you can see, am managing to get once every 2-week dialysis because of the high cost of the machine treatment and transportation. Sometimes I have to stay with my in-law in Makurdi for a long time to cut down transportation cost. My brother who is helping me is not able to meet up with the cost again. He has his family”-participant R;
 “I thought it’s only machine money I needed to spend, but each day I come here, my blood is short (anaemia), “I have to get blood (blood transfusion), which cost \$7000/pint, things are not easy with me at all”- Participant B.

Sub-theme 9: Loss of Job: Some of the major reasons the participants reported about financial difficulties were lack of physical strength, loss of job, lack of employment and lack of national health insurance scheme (NHIS) packages.

“At my age (67 years) where do I get the strength to work again for money?” - Participant S;
 “At first, they used to give me chance from my workplace for dialysis, but later they told me to go and face my treatment without any financial assistance” – Participant R;
 “I have no job, I have sold all my properties, I have sold my car at a very small money including my goats because of this sickness and for washing of my blood”- Participant J; “even my drugs were purchased by my friend, because I don’t have any work to do to earn money “– Participant B

Sub-theme 10: Lack of medical subsidy package
 “I know about NHIS, but our organization did not enroll us. Our government did not do anything to reduce the price of the haemodialysis. These politicians do not know what the poor people like us are facing” -participants G, N reported.
 "For the poor rats (people) like me, hardly get even once a week haemodialysis because, we don’t have the money to pay for it, but if the government has taken steps to make it more affordable, perhaps a lot of lives can be saved."- Participant B

Furthermore, due to the high financial demand the haemodialysis treatment imposed on these participants, they described the treatment as treatment of poverty.

Psychological lived experiences of patients undergoing maintenance haemodialysis at the Benue State University Teaching Hospital, Makurdi.

Table 5: Theme 4 and Sub-Themes

S/n	Theme 4	Sub-themes
4	Psychological Lived Experience	1. Psychological Torments
		2. Life of Uncertainty
		3. Am Prepared

Sub-Theme 11: Psychological Torments- The participants revealed that, they experienced a wide range of mental disturbing agonies in reaction to the news that haemodialysis treatment is for the rest of their lives. Such expressions included depression, anger, frustration, sadness, and worries which affected their mental health.

For instance, participant A claimed that,
 “After learning about the severity of the disease condition and the prolonged treatment, I was in deep shock and depression...in fact, words cannot truly express the agony of my situation.
 “I used to worry a lot in the initial phase of dialysis, even now, I don’t know whether am getting back to myself?” – participant D
 “I have a 1-year boy and I would like to live for another 10 years more, so that he can see his father” –Participant C
 “When I look at my body carrying plaster on my neck, hands and see all my body swollen, it breaks my heart because I was not like this, I was lanky, different and could never go back to be the same” - participant F.

Sub-Theme 12: Life of Uncertainty - Unpredictability is a key element in all chronic illnesses and is defined as a cognitive state in which the individual is unable to categorize the meaning of the illness-related events (29). The majority of the participants stated that, they do not really know whether the machine treatment could help them to live long with a good quality life, remained dependent on haemodialysis or even die any moment in time. For instance, various participants reported one thing or the other as seen below:

“I don’t know what will happen between now and in the next moment...At times my mind goes dark, other times I thought I could get well soon and live a good quality of life but at the same time, I start thinking about my death. Can you understand how painful it is to live in a situation between life and death?”.... Sobbing!!! -participant L
 “Do you know that I think about death every second of life I have? This is stressing me up and is painful”- participant T

Sub-Theme 13. Am Prepared- This sub-theme emerged from most of the study participants’ description of ways they spoke in order to cope with the long journey of dialysis treatments. They uttered words such as:

“Whatever happens”- participant A;
 “Am already fulfilled in life...all my children have started their family life”- participant C;
 “I have settled all my children... I have built houses for them”-Participant P;

“I have already written out my will”-Participant J;
 “whatever Allah (God) wishes” – Participant H;
 “In spite of all these difficulties, believe in my faith” – Participant O;
 “My husband still loves me...so am ok, he still calls me my baby”-Participant I.

Discussion

End stage renal disease patients require haemodialysis treatment for the rest of their life particularly in the low- and middle-income resource regions or until they receive a successful kidney transplant [21]. Despite recent great advances in nursing and medical technologies, haemodialysis is still not without severe complications during or after treatment sessions as it can lead to many health-related problems that compromise the quality of life [30].

Regarding socio-demographic characteristics of the studied participants, the majority of the participants were male. This finding corroborates with Garcia *et al*, [31] in his study on “Sex and gender differences in chronic kidney disease and access to care around the globe” who concluded that, males have higher haemodialysis prevalences than females. Again, the study reviewed that, the elderly had higher incidence of haemodialysis than the younger participants. This finding is congruent with Ko *et al* [32], which in his study on “Factors Associated with Withdrawal from Dialysis Therapy in Very-Elderly Incident Hemodialysis Patients” concluded that, there was high incidence rate of haemodialysis treatment among the elderly than the young people. More than half of the participants were married. This finding also agreed with Togay and Akyüz [33] on “Examinations of effects of socio-demographic features and disease-related data of patients with haemodialysis on the quality of life” reported that, 78.4% of the study participants were married. The majority of the study participants optioned Christianity as their religion. This finding was in the same line with [34] study on “Religious coping and hope in chronic kidney disease: a randomized controlled trial, Brazil”, which he concluded that, prayers as one of the religious practices/beliefs served as a positive coping strategy among haemodialysis patients. Most of the participants had acquired secondary school education, which could affect their health seeking behavior. Wahyu *et al*, [35] in his study on “Effect of Education on Life Quality of Haemodialysis Chronic Kidney Failure Patient in Dr. Yunus Hospital Bengkulu City, Indonesia”, had earlier concluded that, education can help any individual patients and the community to improve their health and thus affect their attitudes toward health. On occupational status, most participants were business oriented which suggests that, most of them would have a source of income to cope with direct and indirect financial costs associated with undergoing haemodialysis treatment. However, this finding does not agree with Ma *et al*, [36], whose study on “Economic burden of maintenance haemodialysis patients’ families in Nanchong and its influencing factors’ stated that, even with various medical insurance systems in place, haemodialysis patients can still experience significant financial hardship.

In relation to the physical lived experiences of haemodialysis, the study participants revealed that, haemodialysis gave them hope to live again, but this hope came with a heavy price as they experienced chronic pains

such as acute muscle cramps, headache, painful ischemic limbs, back pain due to long hours of lying down on the machine chairs, during haemodialysis procedures, vascular access creation, and taking of blood samples. As such, they wished if tablets were given for healing instead of haemodialysis treatment. Earlier study conducted by Kuo *et al.*,^[37] on “Cramping, crashing, cannulating, and clotting: a qualitative study of patients’ definitions of a “bad run” on haemodialysis” confirmed this study, that, haemodialysis patients suffer from various degrees of physical problems including physical body pain from procedures, muscle cramps, abdominal cramps and headaches.

Concerning nausea/vomiting, more than half of the study participants experienced it. In an earlier study conducted by Fathurrohman and Suparti^[38] on “Analysis on factors affecting nausea and vomiting severity suffered by patients in the early phase of hemodialysis therapy, Indonesia,” they arrived at the similar result and further concluded by stating that, patient's diet and excess fluidity are among the causes of nausea and vomiting in hemodialysis patients.

Regarding physical fatigue as expressed by most of the participants, this finding is not different from Wang and Tong^[39] whose study on “Life experiences of long-term haemodialysis patients: A descriptive review” concluded that, haemodialysis patients suffered from lack of energy, fatigue and burnout after dialysis, and are unable to complete normal work as it takes longer time to recover from dialysis weakness.

Another important finding of this study also revealed that, more than half of the study participants suffered from hypertension. Ali *et al.*,^[40] in his study on “Frequency of Intradialytic Complications in Patients of End-Stage Renal Disease on Maintenance Haemodialysis, Karachi, PAK” concluded that, hypertension was the second most common lived experiences of patients on maintenance haemodialysis. According to Bansal *et al.*,^[38] the reasons for commonality of hypertension among haemodialysis patients may not be far from fluid volume overload due to regulatory failure of the kidneys, high intake of table salts, inter-dialysis weight gain, enhanced activity of the sympathetic nervous system, renin-angiotensin-aldosterone systems, endothelial dysfunction, and use of erythropoietin-stimulating agents.

Away from the physical lived experiences, the information elicited from study participants also revealed that, living with end stage renal disease and going for its long-life machine treatment has left them with a huge social lived challenges in uncountable ramifications. Social lived detachment is one of those challenges faced by haemodialysis patients as revealed in this study. This finding is in consonant with Raj *et al.*^[40] who reported that, although haemodialysis helps patients to live longer, they experience social isolation. The study findings also unveiled that, patients on chronic haemodialysis suffer from social lived dependence, where they socially depend on nephrology nurses, nephrologists, hospital attendants for treatment and good emotions. This revelation is in harmony with the study earlier carried out by Bhattarai and Sharma (1) on “Lived Experiences of Patients with Haemodialysis in Chitwan, Nepal” in which he concluded that, haemodialysis patients depend on nurses, doctors, family members and good friends for association. The study findings also uncovered the fact that, haemodialysis patients suffered from social lived limitations. This finding is supported by Alzahrani *et al.*^[42]’s study on “The Lived

Experience of Middle-Aged Saudi Patients with End-Stage Chronic Renal Disease on Haemodialysis Treatment, Saudi Arabia” in which he concluded that, haemodialysis patients find social engagement difficult, and that they cannot fully meet their family responsibilities due to fatigue old age and long hours on haemodialysis machines.

Economic lived experiences of patients undergoing maintenance haemodialysis at the Benue State University Teaching Hospital, Makurdi became another important theme in this study. All the participants expressed various worrisome concern over financial difficulties and how it affected their quality of life as they could not do 3 times a week haemodialysis in accordance with the world best practices. This discovery is parallel to one of the most recent studies carried out by Kausar and Mazhar^[43] on “Capturing the Phenomenological Perspective of Patients with Chronic Kidney Disease Undergoing Hemodialysis in Gujrat, Pakistan” where due to budgetary limitations, the majority of participants reduced the frequency of their haemodialysis services they received to once a week and the thought of high cost of haemodialysis constantly got them saddened. The finding also revealed that, due to financial difficulties, some of the study participants withdrew from haemodialysis treatment. This finding also agrees with Akpan *et al.*,^[44] whose study on “Demographics, Cost, and Sustainability of Haemodialysis among End-Stage Kidney Disease Patients in Southern Nigeria: A Single-Center Study” documented that, most patients could not sustain haemodialysis beyond a few weeks for financial reasons.

Loss of job was one of the major reasons for financial difficulties while undergoing maintenance haemodialysis as revealed by the study participants. Kausar and Mazhar’s^[43] study on ‘Capturing the Phenomenological Perspective of Patients with Chronic Kidney Disease Undergoing Haemodialysis in Gujrat, Pakistan” alludes to the fact that, loss of employment exacerbated significant financial burden of haemodialysis patients. Following the loss of job, the patients resorted to sale of household goods to fund the medical bills thus making them extremely poor. This finding is in congruent with the study carried out by Gebrie *et al.*,^[21] on the “Patients’ experience of undergoing maintenance haemodialysis. An interview study from Ethiopia” in which study participants reported that, their diseased condition and its costly treatment had caused them to lose the wealth they had earned over their lifetimes. On this same point, The Kidney Foundation of Canada ([KFOC], 45) alluded to the fact that, nearly 50% of annual household income of the study participants significantly decreased since starting haemodialysis treatment.

Lack of medical subsidy package was another significant reason for suffering untold financial crisis while undergoing chronic haemodialysis as uncovered from the study participants. This finding aligns with Okoye and Mamven’s^[46] study on “Global Dialysis Perspective: Nigeria” in which they posited that, the resource allocated to health in Nigeria is poor, and there is no meaningful government support for haemodialysis patients. Study by Nwanaji-Enwerem *et al.*,^[7] strongly supported the above point as they reported that, the operational guideline of National Health Insurance Scheme (NHIS) Nigeria, spelt out 6 sessions of haemodialysis for the acute cases only. This partial inclusion excludes those on maintenance haemodialysis and cost of other services such as fistula/access creation, erythropoietin, calcium supplements, phosphate binders, blood transfusions and

blood pressure medications which are some of the necessary hidden charges associated with haemodialysis treatment. Meanwhile, earlier study by Luyckx *et al* ^[47] on the “Dialysis funding, eligibility, procurement, and protocols in low- and middle-income settings: Results from the International Society of Nephrology Collection Survey” concluded that, hemodialysis in the low and middle-income settings is characterized by “No money, no life; and that, life and treatment are only limited by money.”

Data on the psychological lived experiences of the study participants revealed that, patients on maintenance haemodialysis suffered from various types of psychological trauma such as psychological torments and others, since they were diagnosed with chronic kidney injuries that needed a prolong haemodialysis. This finding is in agreement with Avdal *et al* ^[48] study on “Opinions of haemodialysis and peritoneum patients regarding depression and psychological problems which they experience: A qualitative study”, which reported that, haemodialysis patients frequently experienced depression and other psychological problems. According to the study participants, many reasons caused the psychological trauma such as loss of job, for lack of energy and time to do the job, being unable to contain with the cost of haemodialysis treatment and other hidden financial charges associated with doing chronic haemodialysis, coupled with the fact that, the government had no national subsidy or reimbursement for patients on maintenance haemodialysis as earlier seen above. This finding is in harmony with Ng *et al* ^[49] whose study on “Association between Financial Hardship and Symptom Burden in Patients Receiving Maintenance Dialysis: A Systematic Review” asserts that, financial hardship due to treatment costs and income loss related to decreased productivity is associated with depression and anxiety in patients with chronic diseases and their treatments. In this study, the chronic disease with its treatment being end stage renal disease and haemodialysis treatment respectively.

Concerning life of uncertainty, the finding revealed that, the majority of the study participants were in a state of precariousness in relation to their ill health and its treatment, living between life and death, desiring a better tomorrow but being in doubt since no one could ever tell them exactly the outcome of their treatment. This finding confirmed the study by Raj *et al* ^[41] on “Enabling good outcomes in older adults on dialysis: a qualitative study”, where he concluded that, haemodialysis patients endure persistent uncertainty of life. “Am prepared” was another major sub-theme under psychological lived experiences as unveiled by the study participant. They reported that, having passed through a lot of suffering, they felt all hope was lost, and so they needed to device a means of coping with what they cannot change since they believed that, whatever Allah (God) wishes, they just have to prepare to accept. This finding is congruent with Gebrie *et al*, ^[21] in his study on ‘Patients’ experience undergoing maintenance haemodialysis: An interview study from Ethiopia” where he alluded to the fact that, the participants accepted the reality of their condition, and believed that it was God who had the power to heal or kill and not the disease.

Application of Theory of Unpleasant Symptoms to This Study

Symptom experience: As earlier mentioned, haemodialysis produces huge negative effect on patients in the form of unpleasant symptoms or otherwise termed lived

experiences. In other words, haemodialysis designed to be the solution to kidney failure has become a problem itself to the population its meant serve. In this study, symptoms experienced included physical pain, physical fatigue, nausea/vomiting, hypertension, social detachment, social lived dependence, social lived limitation and others.

Influencing factors: included physiological, psychological, and situational factors. In this study, the physiological factors were such as age meaning, the more advanced in age, the more severe were the physical fatigue, physical pain and so on. Another physiological factor was gender of which most were male. The third physiological factor was the failed kidneys which affected entire participants making them unable to adequately remove excess waste, excess fluid, and electrolyte balance that eventually led to haemodialysis treatment which in turn triggers unpleasant symptoms. The psychological factors in this study were the psychological torments, life of uncertainty and am prepared. The other influencing factors that worsened the symptoms of participants were situational factors such as financial difficulties, loss of job and lack of medical subsidy packages.

Consequences of symptoms: Unpleasant symptoms produced either by the disease process (ESRD) or from the treatment (haemodialysis procedure) as revealed in this study resulted to the following: life of chronic physical pain and hypertension etc. Economically, financial hardship forced some of the patient to withdrawal form haemodialysis treatment eventually leading to death. Some employers who noticed that, their employees have become physically incapacitated, and cannot cope with job stress associated with their task, relieved them of their job, while others were forcefully subjected to early retirement. Socially, the chronicity of symptoms produced by the haemodialysis treatment caused patients to withdraw from social activities like participating in public prayers, weddings and exhibitions (Lived social detachment). Psychologically, the knowledge and understanding that, haemodialysis treatment is not a cure, and that, the haemodialysis procedure is for life, led to consequences such as psychological trauma such as hopelessness, helplessness, suicide ideation and so on.

With a comprehensive knowledge and use of the theory of unpleasant symptoms, the renal nurses could coordinate the activities of multi-professional health teams such as psychologists and psychiatrists (to address anxiety and depression), dieticians (fluid and salt restrictions) physiotherapists (address the issue of exercise) social health workers (advocate for funds) and nephrologists (treat physical complications and infections) to give quality care in order to limit these factors from worsening the unpleasant symptoms experienced thereby, improving the quality of life ^[50].

Implication to nursing

- This study would serve as the knowledge base for the educational purposes to both nursing students and staff
- It will help nurses to see good health of their client as an economic good for social development and as a prerequisite to the attainment of health for all.
- The lived experiences of haemodialysis patients are not different from signs and symptoms. As such, registered

nephrology nurses will take advantage of the rich knowledge in this study to proactively assess, diagnosed correctly to initiate accurate intervention measures to alleviate the suffering of hemodialysis patients, and also not forgetting to evaluate their actions to see if they impact positively the quality of life in their patients.

- The research has great potentials to help address the excesses of nurses' attitudes that can hinder service uptake by hemodialysis patients or even worsen their health situation.
- Application of the theory of unpleasant symptoms (TUS), a new theory, that guided the research could be used by nurses particularly in the clinical settings to logically describe, explain, predict symptoms and timely prepare adequately for appropriate intervention.
- The internalization of this research knowledge can stir up the sleeping advocative, educative, collaborative, counselling roles of the nurse that could be of several help to hemodialysis patients and their informal caregivers.

Limitations

There was high attrition, coupled with exclusion criteria among the study participants resulting to extension of data collection period.

It was so difficult to find a suitable time for data collection from the study participants.

Getting the ethical clearance approval from the health research ethics committee, Benue State University Teaching Hospital was met with a lot of managerial red-tapism and took more than 2 months thus making it impossible for the researcher to get early into the field for data collection.

Conclusion

Based on the findings of this study, lived experiences of patients on maintenance haemodialysis at the Benue State University Teaching Hospital Makurdi ranges from physical pain, nausea/vomiting, physical fatigue, and hypertension. Other unpleasant symptoms of these patients included social life detachment, social life dependence and social life limitations. Furthermore, these patients suffered from financial difficulties, loss of job and lack of health subsidy packages. Psychological torments, life of uncertainty and "am prepared" adversely affected the quality of life of patients on maintenance hemodialysis. However, the adoption of theory of unpleasant symptoms in the clinical area by nephrology nurses can go a long way to mitigate these unpleasant symptoms thereby giving these patients hope of living again thereby improving their quality of life.

Recommendations

Based on the findings, the following recommendations were made

Nephrology nurses need to familiarize themselves with the use of the principles of the theory (TUS) that guided this study in the implementation of the nursing process, thus help in improving the quality of care of hemodialysis patients.

That, nurse researchers and those in the clinical area should consider the use of theory of unpleasant symptoms, an emerging theory, in their research studies and care of patients, particularly patients with chronic conditions/treatment.

Nephrology nurses need to educate hemodialysis patients about the unpleasant symptoms and the need to accept them as part of the outcome the machine treatment.

Nurses, other health workers, the family, similar patients, friends and the community at large should give physical, social, economic and psychological support to hemodialysis patients as this will impact positively on their quality of life.

From an economic and political viewpoint, the health facility administrators, health policy makers should collaborate with federal government of Nigeria to make hemodialysis service free for all patients on maintenance treatment thus minimizing catastrophic health expenditure for hemodialysis.

The federal government of Nigeria should also make adequate provision for other modalities of renal replacement therapy (RRT) such as peritoneal dialysis which can help improve cost efficiencies in the majority of patients as they live in low and middle-income region.

While that effort would be going on, the federal government of Nigeria should collaborate with international agencies for funding and training of nurses, physicians and technicians on the necessary skills needed for operations in the modern medical technology in nephrology.

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Conflict of interest statement

The authors declare that, there are no conflicts of interest related to the current manuscript.

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