
Lived Experience of the Burden of Chronic Kidney Disease Among Patients Receiving Treatment in Naval Hospitals in Lagos Nigeria

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ABSTRACT: *Chronic Kidney Disease (CKD) is a complex condition that requires ongoing management and treatment, which can significantly affect the quality of life for patients. The aim of the study explored the lived experience of the burden of CKD among patients receiving treatment in Naval Hospitals Lagos Nigeria using a phenomenological research design. A total of 12 participants were selected using a purposive sampling technique. Data was collected with an unstructured one-on-one interview using open-ended questions lasting for about 30 minutes on each participant. The researcher ensured reliability of the data by adhering to the rigors of a qualitative research. Structural analysis and in-depth interpretation of meaning to understand the lived experiences of the participant was done to generate themes using Colaizzi phenomenological method of data analysis. From the interview, five themes emerged which reflected on lived experiences of patients living with CKD. The findings from this study indicated that financial constraints, restricted life, psychological influence was evident where there were many shared experiences. Inaccessibility to social support service was a major challenge and an extra expense. It also identified building inner strength, family, and spiritual support and prayers as integral components of coping strategies. It is therefore recommended that, routine social and psychological support services and interventions should be incorporated into the care of CKD patients by providing access to counseling services, support groups, and mental health support.*

KEYWORDS: chronic kidney disease, coping strategies, dialysis, lived experiences

INTRODUCTION

Chronic disease may affect the patient and carer psychologically, economically, socially, and physically. Chronic Kidney disease (CKD) is considered a significant health concern in public health and is classified as a non-communicable illness in modern medicine. The World Health Assembly aims to decrease the incidence and death rate caused by chronic diseases by 25% by

2025 as part of the Global Action Plan for the Prevention and Control of Non-Communicable illnesses 2013–2020. In 2017, there were 6975 million cases of Chronic Kidney Disease (CKD) worldwide. Approximately one-third of CKD patients resided in India (115 million cases), China (132 million cases), and other countries such as Bangladesh, Brazil, Indonesia, Japan, Mexico, Nigeria, Pakistan, Russia, the USA, and Vietnam, each having over 10 million cases of CKD (Boris et al, 2020).

In 2017, the worldwide prevalence of Chronic Kidney Disease (CKD) was estimated at 9.1% over the total population, with stages 1-2 accounting for 5.0%, stage 3 for 3.9%, stage 4 for 0.16%, and stage 5 for 0.07% (Boris et al, 2020). The global all-age mortality rate from Chronic Kidney Disease (CKD) rose by 41.5% between 1990 and 2017, with 1.2 million deaths attributed to CKD in 2017 (Boris et al, 2020). The prevalence of Chronic Kidney Disease (CKD) in Africa varies from 2% to 41%, and in sub-Saharan Africa, it ranges from 2% to 14% (Abd-ElHafeez et al, 2018). The prevalence of Chronic Kidney Disease (CKD) in Nigeria varies from 1.6% to 12.4%, with a frequency of 51.7% among professional male long haul truckers in Lagos (Amadi et al, 2019).

Research has shown that Chronic Kidney Disease (CKD) may occur at any age owing to the wide range of individuals affected, although the risk considerably rises with age (Liu et al, 2021; Kovesdy, 2022; Aleksandar et al, 2022). In Nigeria, 6%–12% of all medical admissions are due to Chronic Kidney Disease (CKD), affecting young and middle-aged individuals (Ulasi & Ijoma as mentioned in Chinyere et al., 2015). Individuals with diabetes, hypertension, or both are at a higher risk of developing chronic kidney disease compared to those without these conditions (CDC, 2017). Kidney illnesses impose a significant economic cost. High-income nations are believed to spend around 2–3% of their yearly healthcare expenditure towards treating end-stage renal illness. Although a significant amount of money was invested, only a very small fraction of the population, less than 0.03%, actually received the therapy (Liyanage et al, 2015).

The responsibility of caring for patients with CKD is becoming more severe, exacerbated by the unstable economic situations in many low to middle-income nations such as Nigeria. Patients with Chronic Kidney Disease (CKD) may endure a significant burden of care that may adversely affect their mental, emotional, physical, social, economic status, and health-seeking habits. The severity of the disease, difficulties in receiving dialysis treatment, financial limitations, restricted lifestyle, feelings of dependence, environmental and life obligations, limited social interactions, disruption of regular work hours, presence of other health conditions, and finding suitable organ donors can all worsen the impact on health-seeking behaviours and self-efficacy (Hailemariam et al, 2021; Hounkpatin et al, 2020). The condition of hospitals in Nigeria might worsen the burden of treatment for patients with Chronic Kidney Disease.

Nigerian Navy Hospitals are known for having world-class standard of care. However, previous studies conducted in Nigeria on the burden of care have been conducted in government hospitals and are majorly by quantitative approaches. As at the time of this study, only one study has been conducted on the lived experience of patients living with chronic kidney disease (Ekuma, 2018) in Nigeria. Hence the need to conduct the study on the lived experience of patients with chronic kidney disease receiving treatment at the Naval Hospitals in Lagos. The specific objectives explored:

1. the lived experience of chronic kidney disease among people receiving treatment in Naval Hospitals Lagos;
2. the psychological experience of living with chronic kidney disease;
3. the socio-economical experience of people living with chronic kidney disease; and
4. the coping strategies of chronic kidney disease among people receiving treatment in Naval Hospitals Lagos.

METHODS

The study adopted a phenomenological research design in exploring the lived experience of the burden of Chronic kidney disease among patients receiving treatment in Naval Hospitals Lagos Nigeria. The study was conducted at two different naval hospitals in Lagos Nigeria which are the Nigerian Naval Reference Hospital (NNRH) Ojo and Naval Medical Centre Victoria Island Lagos. The sample size was determined by data saturation. However, based on the number of patients attending the hospitals for chronic kidney disease and sample found in literature (Tadesse, et al., 2021), the researcher used 12 patients.

Data was collected with an unstructured one-on-one interview using open-ended questions lasting for about 30 minutes on each participant. Data collection was done bedside the patient in a well-lighted environment, the patient was asked to move to a room prepared by the head nurse for the interview. The interview was audio-taped, and it lasted for at least 30 minutes. Prior to data collection, the researcher obtained ethical approval from the Research Ethics Committee of Naval Hospitals in Lagos after an introductory letter. Also, individual informed consent was obtained from each respondent. All information was treated with the utmost confidentiality, and it was strictly for academic purposes. The data was analysed using Colaizziphenomenological method of data analysis. The Colaizzi method emphasizes the importance of bracketing one's own biases and assumptions and allowing the participants' experiences to guide the analysis. The researcher allowed each person to express their opinion and experiences without any expert knowledge

RESULTS

The survey respondent's socio-demographic characteristics were presented while the lived experiences were presented in themes

Table 1: Socio-demographic Characteristics of the Respondents

Variables	Frequency	Percentage
Age in years		
Less than 20	1	8.3
20 – 30	3	25.0
31 – 40	7	58.3
41 – 50	1	8.3
Gender		
Male	2	16.7
Female	10	83.3
Religion		
Islam	4	33.3
Christianity	8	66.7
Ethnicity		
Yoruba	4	33.3
Hausa	2	16.7
Igbo	4	33.3
Others	2	16.7
Educational attainment		
No education	0	0
Primary	0	0
Secondary	0	0
Tertiary	12	100
Occupation		
House wife	1	8.3
Business	4	33.3
Civil Servant	3	25.0
Military Personal	4	33.3

As illustrated in Table 1 more than half 7 (58.3%) of the respondents were within the ages of 31 and 40 years as against 3 (25.0%) who were between 20 and 30 years and one of the subjects is below the age of 20 years. Majority of the respondents 10 (83.3%) were females as against 2 (16.7%) who were male and two-third 8 (66.7%) were Christians. Christians form the bulk of the respondents of the sample and this may not be unrelated with the fact that Christianity is relatively widespread across the study region. On the aspect of the participants' ethnicity, one-third 4 (33.3%) of them were Yoruba and Igbo respectively. The high proportion of the Yoruba and Igbo may be explained by the widespread distribution of the ethnic groups across the study location. All the participants 12 (100%) possess had tertiary education ranging from diploma to degree certificates and one-third 4. (33.3%) of the patients were businessmen and women and military personnel as against 3 (25.0%) who were civil servant.

Table 2: Socio-demographic Characteristics and Impact of CKD on participants

Variables	Frequency	Percentage
Employment Status		
Employed	7	58.3
unemployed	1	8.3
Self Employed	2	16.7
Retired	2	16.7
Duration of oldest chronic condition		
Less than 5 years	10	83.3
5–10 years	2	16.7
Duration of Chronic Condition		
Less than 5 years	10	83.3
5 -10 years	2	16.7
11 years and above	0	0
Duration of CKD		
0 -3 years	9	75.0
4 - 6 years	3	25.0
7 - 9 years	0	0
10 and above		
11 and above	0	0
Number of dialysis session during the last month		
less than 3 times	7	58.3
3 - 5 times	4	33.3
6 and above	1	8.3
Income per month (₹)		
No income	0	0
less than 50000	5	41.7
50000 – 100000	4	33.3
More than 100000	3	25.0
Smoking Status		
Never smoke	12	100
Former smoker	0	0
Current smoker	0	0
Alcohol Drinking Status		
Never drink	8	66.7
Former drinker	1	8.3
Current drinker	3	25.0

As indicated in Table 2, the study found that the majority of the respondents were employed (58.3%), while only 16.7% were self-employed or retired. Most of the respondents (83.3%) had duration of one to four years of the oldest chronic illness before the onset of chronic kidney disease. Additionally, 75% of the respondents reported that the onset of CKD was between 1 to 3 years. In terms of dialysis sessions, 58.3% of the respondents had one to two sessions during the last month, while 33.3% had three to five sessions. Regarding monthly income, 41.7% of the respondents earned less than N50, 000.00, while 33.3% earned between N50,000.00 to N100,000.00. The majority of the respondents reported that they have never smoked (100%), and 66.7% of them also reported that they have never consumed alcohol, while 25% were current drinkers of alcohol.

Table 3: Themes and sub-themes

Themes	Sub-themes
1. The Burden of Living with CKD	Loss of income Dietary restrictions Constant fatigue Dependency on others
2. Social Impact of Living with CKD	Loss of friends Social Isolation
3. Economic Impact of Living with CKD	Cost and frequency of dialysis
4. Psychological Impact of Living with CKD	Anxiety and loneliness
5. Coping strategies of living with CKD	Trust in God Family support

The results were grouped into 5 themes.

Theme One: The Burden of Living with Chronic Kidney Disease

Living with chronic kidney disease(CKD) is a significant burden for individuals and their families. The disease is a long-term condition characterized by the gradual loss of kidney function overtime. As the disease progresses, it can have a profound impact on various aspects of a person's life, both physically and emotionally.CKD can affect an individual's ability to work or pursue employment opportunities. At the Nigerian Navy Reference Hospital (NNRH) Ojo one of the participants(participant4) when asked about his burden living with chronic kidney disease, he said:

Uh-uh, this condition has affected me so much that I don't go to work again. It has affected me due to the income... That day I was so broke, I don't have transport money, to transport myself to my workplace. I just called my oga and I informed her, and she said I should relax for awhile. But at least I was able to get transport and transport myself down to my workplace. I don't go to work again, and I can't achieve all my target goals again because of the disease. (Participant 4)

Dietary restrictions and treatment regimen of the disease were reported as overwhelming by CKD patients as highlighted by participants one and five

Because of my present condition, I was told not eat foods that contains salts and proteins. This food that I must not take again has affected my life. As I speak with you now, I can't eat some of the foods even if I have the appetite on it. I have no choice than to manage because it is going to make my condition worst. (Participant 1)

I'm not finding it easy oh my sister. The medicine I'm buying to treat myself and the payment for this machine(Dialysis machine) is giving me sleepless night. Sometime, I have to go and borrow money from people to ensure that I buy the drugs that doctors write for me. It has not just been easy with me. I pray for divine intervention (Participant 5).

Constant treatment of the disease and fatigue were depicted to affect their physical activities, and struggling with tasks that were once effortless. Simple activities become challenging and exhausting to them.

Participant 11 stated that:

I no dey fit do things for myself again. Any small thing I do, I don tire. This disease has affected me so much now that most of the work, I can't do them again. Infect, my sister had to come and stay with me to be assisting me in doing most of the housework. (Participant11).

Participant 6 also narrated that:

If there is anything that I always think about is how to get money and donor to treat my condition. As you can see I have lost some weight because of thinking... It is not easy with my life. Now as I speak with

you, please just pray for me to overcome this situation. (Participant 6)

Themes Two: Social Impact of Living with Chronic Kidney Disease

Struggle with social activities, feelings of isolation, a reduced ability to engage in social relationships, and a sense of disconnect from their previous social networks were the major issues mentioned as a restrictive factors and other supportive care were described as social impact.

Theme Three: Economic Impact of Living with Chronic Kidney Disease

Financial burden and demands due to the costs of medications, treatments, frequent medical visits, and potential hospitalizations. Majority of the respondents believed that treatment of the disease has financial constraints on them. Most participants described the frequency of dialysis sessions within a week and cost of medications as a serious burden on them as expressed below.

Theme Four: Psychological Impact of Living with Chronic Kidney Disease

Living with CKD can have a significant emotional impact. Individuals often experience a range of emotions, including frustration, sadness, anxiety, and fear. Many of the participants narrated their psychological feelings on how CKD has affected lives.

Theme Five: Coping Strategies of living with Chronic Kidney Disease

Many of the participants interviewed shared various coping strategies they use to navigate the challenges of living with CKD, such as maintaining a positive mindset, practicing mindfulness or meditation, engaging in hobbies, and seeking peer support. Some of the participant stated that they usually seek emotional support from family, friends, or support groups. Relying on family and close friends for emotional support, understanding, and practical help with daily activities.

DISCUSSION

The study investigated the lived experience of living with chronic kidney disease receiving Treatment at naval hospitals in Lagos. According to the study, living with CKD is a significant burden for them and their families. Dietary restrictions and treatment regimen of the disease were reported as overwhelming by CKD patients. Constant treatment of the disease and fatigue were depicted to affect their physical activities, and struggling with tasks that were once effortless. Simple activities become challenging and exhausting to them. This study finding was in line with the study conducted in Nigeria by Ekuma (2018) where participants described the loss of their freedom to participate in different activities restriction in diet, fatigue associated

with a lack of strength and energy, and decreased ability to perform their jobs as a serious burden affecting their lives with CKD. In this study, participants clearly described their immense sense of loss on multiple dimensions. The finding of this study was also supported by Cooper (2017) who reported that patients who frequently need dialysis can be very difficult to care for both inside the hospital and at home. Hussien et al., (2021) established that the systemic effects of CKD can have a negative impact on a patient's health and quality of life, making them feel like a burden to their loved ones and the community.

The result of the study shows that struggle with social activities, feelings of isolation, a reduced ability to engage in social relationships, and a sense of disconnect from their previous social networks were the major issues mentioned as a restrictive factors and other supportive care were described as social impact. The finding of this study is in agreement with that of Griva et al (2016) where he reported that social relationships among patients with chronic kidney disease are commonly poorly impacted. Many studies have revealed that the presence of a chronic illness is a very stressful life event and can create significant social problems for patients and their caregivers. This finding was also supported by the study of Sahafet al (2017) where they reported that CKD disturbed participants in the performance of their roles in families and community while impacting their ability to plan.

The current study showed that the financial burden and demands due to the costs of medications, treatments, frequent medical visits, and potential hospitalizations. Majority of the respondents believed that treatment of the disease has financial constraints on them. This finding was consistent with a study conducted in Nigeria by Oluwademilade et al, (2020) who reported that CKD and its treatments can impose financial burdens on individuals and their families. Medical expenses, including medications, dialysis, and transplantation, can be significant. Moreover, individuals may face challenges in maintaining employment due to the demands of treatment, fatigue, and physical limitations. Financial stress adds an additional layer of burden to the lived experience of individuals with CKD. Most participants described the frequency of dialysis sessions within a week and cost of medications as a serious burden on them. Bamgboye, (2014) findings is similar with the current study where he reported that, Nigeria, only 1% of patients can afford treatment for longer than three months due to financial constraints. In Nigeria, the price of dialysis is between 100,000 and 150,000 Naira only.

This study showed that participants often opted for various coping strategies to navigate the challenges of living with CKD, such as maintaining a positive mindset, practicing mindfulness or meditation, engaging in hobbies, and seeking peer support. These findings were supported by Yaman and Ayaz (2016), who also confirmed that praying was the most popular coping approach for them. Another paper asserts that spirituality enhances life quality by fostering a strong social support system, developing adaptive coping mechanisms, reducing depressive symptoms, and enhancing bodily functions. The supportive responses of family and friends to the physical

changes those patients underwent throughout treatment helped them deal with psychological issues and disruptions to their body image. Also, the need of spirituality in coping with the fatal illness and adapting were reiterated (Anderson, 2021; Esan et al., 2020). Hounkpatin et al., (2020) finding is also similar with the current study finding.

CONCLUSION

The lived experience of patients living with CKD is characterized by numerous challenges and impacts on their physical, psychological, financial and social well-being. Significant negative narratives from the participants in this study were reported. Financial constraints, restricted life, psychological influence was evident where there were many shared experiences. Inaccessibility to social support service was a major challenge and an extra expense. Restrictions from available foods and drinks were a double burden that limited participants from using an available resource.

CKD is a complex condition that requires on-going management and treatment, which can significantly affect the quality of life for patients. Through understanding the lived experiences of these individuals, healthcare providers and policy makers can develop strategies to improve care and support for CKD patients.

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