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Lived Experiences of Chronic Kidney Disease Patients undergoing Haemodialysis in a Tertiary Hospital of Nepal

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ABSTRACT

Background: Chronic kidney disease (CKD) poses significant global health challenges, including in Nepal, where the increasing need for hemodialysis are influencing patient's daily life. This study aimed to explore lived experiences of CKD patients undergoing hemodialysis.

Methods: A qualitative, phenomenological research design was employed. In-depth interviews were conducted with 13 hemodialysis patients at Bir Hospital from December, 2023 to January, 2024. Analysis followed Colaizzi's method, ensuring data quality through established credibility and transferability measures.

Results: Four major themes emerged: (i) Journey to receive hemodialysis (ii) Financial Constraints (iii) Psychosocial support (iv) Seeking for special health services. Patients perceived hemodialysis as a hope for existence but faced financial troubles and inadequate special and psychosocial support.

Conclusions: The lived experiences of the patients reflected both hope and challenges highlighting the need for improved health services and counseling in hemodialysis wards, along with enhanced governance in the healthcare system.

Keywords: Chronic kidney disease; hemodialysis; lived experience; pilot; qualitative.

INTRODUCTION

Globally, over 850 million people are affected by chronic kidney disease (CKD), claiming over 3.1 million deaths in 2019, making it an emerging global health problem.[1, 2] It is currently the eighth greatest cause of mortality and is expected to become the fifth major cause of mortality by 2040 if timely treatments are not provided.[1, 2]

CKD prevalence in South Asia includes 10.2% in India, 10.6% in Nepal, 17.3% in Bangladesh, and 23.3% in Pakistan.[3] In Nepal, 8,000 CKD patients are undergoing haemodialysis (HD); this number continues to rise burdening the healthcare system.[4] HD is essential in patient longevity but impacts lives in various ways.[5] HD can cause many physical and mental health complications[6] and health care providers need to understand CKD patients' lived experiences to provide better support.[7,8] With limited research on CKD patients' experiences, this study aimed to explore lived experiences of the CKD patients undergoing HD in a tertiary hospital of Nepal.

METHODS

This study is a pilot study that explores the lived experiences of chronic kidney disease patient treated with hemodialysis. The purpose of the pilot study is to test the feasibility of the research design, refine data collection methods, and assess the adequacy of the interview guidelines and determine whether the analysis method is adequate before expanding the study to a larger participant.

A qualitative, phenomenological research design was carried out among CKD patients who were receiving HD from Bir-hospital, National Academy of Medical Sciences

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(NAMS), Kathmandu, Nepal.

The study participants included patients with CKD undergoing HD for more than six months, both male and female, aged 20 years or above, speaking Nepali language and consented to participate. Patients with acute renal disease and having dementia and critically ill (severe and life- threatening conditions) were excluded from the study.

A total of 13 participants were purposively selected, and in-depth interviews were conducted using a semi structured interview guidelines and audio recordings from December, 2023 to January, 2024. Written informed consent was obtained from each participant and special permission was obtained for the audio recording. Interviews lasted for 45 to 90 minutes. The interviews process continued until it was clear that no additional concepts or themes were emerged.[9]

Ethical Approvals were obtained from Nepal Health Research Council (NHRC-Ref. No. 361/2023/2024) and Bir-Hospital/NAMS (Ref.No.540/2023/2024), Kathmandu, Nepal. Additionally, administrative letter was received from the Sharda University, School of Nursing Science and Research (F. No: SSNSR/Letter/2023/478), Greater Noida, India.

Data collection and data analysis were performed simultaneously. The whole analysis process was carried out by following Colaizzi's (1978) seven steps of analysis.[10] The Consolidated Criteria for Reporting Qualitative studies (COREQ) 32-item check list was followed to ensure reporting consistency.[11]

The quality of the data was ensured by following the Lincon and Guba (1985) approaches.[12] The data was collected until it got saturated and verbal and nonverbal expressions of the participants were noted during and after interview. Similarly, confirmability was ensured by maintaining the relevance of meanings during the process of transcriptions and discussing with qualitative research experts and team members.

RESULTS

Among thirteen participants, seven were male, six participants belonged to age of 40 to 50 years, other six were between 30 to 40 years of age and one is below 30 years of age. Eleven participants were married, eight had completed a Bachelor's degree, three had studies up to 10th grade, and two were illiterate. Almost all participants were residing in rented home, and eleven participants depended on their family for income. Two participants were undergoing HD for more than 10 years and eight participants between 1 to 5 years. Eleven participants were undergoing HD for 2 times a week. Regarding comorbidities as self- reported by participants, all participants had hypertension (HTN), three had thyroid problems, other three had cardiac problems and only one had diabetes mellitus (DM).

Table 1 summarises the four major themes and the sub-themes emerged from the patients' lived experiences undergoing HD.

Table 1. Emerged Theme on Lived Experiences of Participants undergoing Hemodialysis.

Themes	Sub-themes
Journey to receive hemodialysis	Illness pattern
	Admitted in hospital
	Reaction on diagnosis and treatment modality
	Struggling to receive dialysis
Financial Constraints	Transportation expenditure
	Unable to purchase needed medicine
	Delay for laboratory test regularly
	Afford for needed food
Psychosocial support	Support from spouse, family and emotional feelings
	Self - motivated
	Diversional activities
Seeking for special health services	Expecting doctor's round in each session
	Need counselling service
	Need of availability of emergency medicines in the ward
	Require well governance

At the beginning, many CKD patients experienced feeling of discomfort, weakness, swollen legs and face, fatigue, sleeplessness, restlessness, anorexia, and shortness of breath. They shared that their laboratory findings indicated low hemoglobin and elevated level of creatinine.

Most patients shared that their diagnosis was a shock, as they didn't anticipate the sudden changes in their lives requiring hospital admission. Many were also unprepared for the treatment modalities involved and expressed guilt over the delayed diagnosis due to their negligence.

One 40-years old male described his situation after hearing his diagnosis and treatment modality *"I was shocked, it was difficult to control myself, I thought that my life is finished, I felt that I had just started to live, enjoying my life and suddenly I could hardly to believe it that I was surrounded by only darkness in my life. I started crying for hours." (P7)*

Almost all participants shared that they faced financial constraints undergoing HD. Many struggled to access HD services promptly, often visiting multiple private and public health facilities, which exhausted their resources. Some had to move from owned homes to rented ones for better accessibility to HD, both in terms of distance and cost. Although the Nepal government provides free HD for longevity, participants noted additional expenses, including medicines, laboratory tests, transportation, and recommended food. More than half mentioned spending significantly on transportation due to long distances, and two participants were unable to complete their evening HD sessions.

A 33-years old male patient stated as *"I discontinued(left) hemodialysis one hour earlier in evening session because my rented house is far from here, if I took hemodialysis for complete duration as four hours it could be late evening and, in that time, it is difficult to get public bus. I have no money to hire private taxi in late evening so I used to do hemodialysis only for three hours instead of four." (P3)*

Some participants are taking antihypertension medicine along with other needed medicines but not taking erythropoietin injection for each session as needed. Participants did laboratory test only when they could afford money. One 38 – years old male participant shared, *"I had to sell all my property to support my treatment. Then, my father sold his land for helping me to continue HD. Now, even my father has nothing left in the name of property. After a few days, I had nothing left to pay for my continued hemodialysis (HD). I ended up fasting for six days, not even taking sips of water." (P2)*

Some participants shared receiving full support from their spouses, while others expressed, they only received financial assistance without emotional support.

A 45-years old female participant narrated, *"I have not received any social support from my family, society, government or non-government organizations. Even my husband also doesn't support me emotionally…… crying…... he provides me just little money. My parents and this free cost of HD save my life." (P4)*

Many emphasized that self-motivation, self-dignity, and self-care were crucial for maintaining their inner strength, alongside external psychosocial support. Some shared that diverse activities helped in spending time while going through difficulties.

One 23-years old female expressed, *"I started meeting the new HD patients and talking to them. Sometimes I started watching face book, you tube and some videos, listening music. All these comforted me and I thought other people also have same problem as mine so these all reduce stress on me." (P12)*

As HD is a delicate procedure, many patients sought specialized care. They expressed concerns and anticipated seeking counseling from various specialists, but often struggled to meet with them regularly.

One 38 - years old male participant narrated, *"I never saw the doctor's face in the ward. I wished doctor took a Round in every session; we are here for 4 hours on HD but the doctor never asked about our health status, any problems. Sometimes, even our medicine is finished and we are not sure whether to continue medicine or not." (P9)*

Many patients also expressed that they felt the counselling about their disease, diet and fluid, fistula care, and stress management were inadequate. Most of the participants encountered some health issues but they could not consult with their doctors during HD. One 47-years old male participant stated *"If we have any health problem, then we need to go to OPD to meet the Doctor. Here in the HD ward, we could not get to meet the doctor...." (P13)*

DISCUSSION

In this study, nearly all participants described their illness pattern, noting that at the beginning, they experienced many health issues including discomfort, weakness, swelling in the legs and face, fatigue, sleeplessness, restlessness, anorexia, and shortness of breath. These findings are consistent with the study conducted in Nigeria where patients identified similar symptoms like swelling of body, anorexia, tiredness, inability to pass urine, vomiting.[13] This study also showed that most patients reported having low hemoglobin, high level of creatinine in blood which is consistent with study done by Lamerato which stated that around one fourth of total participants had anemia and its prevalence increased with CKD stage.[14] High creatinine as stated in this study is also consistent with other studies reporting more than 13.5

mg/dl in blood creatinine, significantly to have CKD. [15]

In the study findings, participants struggled to receive hemodialysis due to lack of accessibility to hemodialysis service for which they had to visit many health institutions and waited for long time. This finding is supported by a study from Ethiopia, which highlighted that the seriousness of the disease requires lifelong treatment, yet there is a lack of accessibility to hemodialysis services.[16]

The participants in this study expressed a range of reactions upon hearing their diagnosis and treatment modality, including shock, hopelessness, restlessness, and crying for hours. These emotional reactions align with the study conducted in Iran, which revealed that some participants initially reacted with shock, crying, and denial, while others experienced feelings of hopelessness, shame, unhappiness and depression, believing that all their desires and goal in life were lost.[8]

This study revealed major issues on financial burden faced by HD patients. They described that they have to pay gross amount of money for the medical expenses including medicines and lab tests. There are several other hidden costs such as transportation fare, boarding for hospital visits and money for medicines and food. Some participants had to sell their property like land, home buildings, gold and others thing for maintaining hemodialysis. This finding is consisted with study done in Ethiopia, which noted that most participants sold their available assets like goat, ox, house, car and others to afford their treatment. Others resorted to borrowing or begging from families, relatives, and/or others. [16]

This study showed that many participants felt mental anguish after starting HD. Some patients expressed feelings of frustration, low self- esteem, loneliness, grief and stress due to life's uncertainty. These findings align with the study conducted in Jordan, in which patients described that they had suffered similar feelings of anxiety, irritability, loneliness and frustration.[17]

Some participants in this study coped with positive thinking towards HD. They engaged in activities such as listening to music, watching YouTube videos about their condition and treatment, and playing mobile games in mobile during the HD sessions. These findings are consistent with a study conducted in Singapore, which reported that positive thinking helped patients mitigate the negative impact of their disease and treatments. [18]

In this study most participants expressed that they lacked continued specialized care and noted that they seldom saw their doctors during sessions. These findings are aligned with a study by Mallik, which highlighted that patients were frustrated with physician communication during HD, feeling that doctors did not give enough time to explain their disease, treatment course and alternatives.[19] In the current study, participants expressed their desire for doctors to have their rounds during their sessions for better communication, however, they had to visit the doctors separately in outpatient clinics instead for communication. Participants wished for more interaction with their doctors and expected to be asked about their health conditions, a sentiment echoed in Mallik's study, which noted that patients were often not even asked how they were feeling.[8] Zhang's study emphasized the importance of providing clear and timely information from trusted healthcare providers, support for self-care, and improvements in services for patients undergoing hemodialysis.[20]

This study allows a deep understanding of patient's subjective experiences within the particular context. It also provides valuable insights and confirms the feasibility of the proposed approach. This groundwork helps in some necessary modifications to the research methodology, ensuring the main study would proceed smoothly and effectively.

The results obtained from a limited, purposefully selected participants may not be applicable to other CKD patients treated with hemodialysis. Furthermore, results have limited relevance to other contexts, as they are specific to the hospital and cultural context in Nepal.

CONCLUSIONS

This study revealed that patients often experienced shock and disbelief upon their initial diagnosis and faced financial and resource constraints during treatment. While patients received mixed psychosocial support, many emphasized the importance of inner strength and engaged in various recreational activities to cope with HD. However, a significant concern was the lack of physician communication, particularly regarding specialized care. These findings offer deeper insights into patients' lived experiences, highlighting the need for improved accessibility, affordability, and availability of hemodialysis care. Further larger studies are necessary to explore these experiences in greater depth.

CONFLICTS OF INTEREST

The Authors declare no conflict of interest.

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