



ORIGINAL

## Echoes of Resilience: Navigating Life's currents through Hemodialysis - Lived Experience

### Ecos de Resiliencia: Navegando por las corrientes de la vida a través de la hemodiálisis - Experiencia vivida

Parameswari.M<sup>1</sup> , Hema.V.H<sup>2</sup> , Seethalakshmi Avudaiappan<sup>3</sup> , Sathiya Priya Viswanathan<sup>4</sup> 

<sup>1</sup>Faculty of Nursing. Dr.M.G.R Educational and Research Institute, Chennai, Tamilnadu, India

<sup>2</sup>Faculty of Nursing. Dr.M.G.R Educational and Research Institute, Chennai, Tamilnadu, India

<sup>3</sup>Sri Ramachandra Faculty of Nursing. Sri Ramchandra Institute of Higher Education and Research, Chennai, Tamilnadu, India

<sup>4</sup>Department of Biochemistry. ACS Medical College and Hospital, Chennai, Tamilnadu, India

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#### ABSTRACT

Chronic Kidney Disease is an emerging Public Health problem impacting the patients overall wellbeing. Prevalence is increasing globally. Hemodialysis being the major treatment modality it imposes great challenges among patients. This study explored the lived experience of Quality of life of patients undergoing Hemodialysis. Phenomenological approach was used among 12 patients undergoing Hemodialysis to explore the experiences of Quality of Life between May 2022 and December 2022. Participants were purposively chosen. Semi structured interview was used to collect the data. Interview was video recorded and transcribed. Thematic analysis was done. Three major themes emerged from the interviews including Physical, Psychological and Social experiences. Various subthemes were identified ranging from physical exhaustion to financial crisis. The exploration of inner being of patients undergoing hemodialysis and assisting them psychosocial interventions will be beneficial in improving their Quality of Life.

**Keywords:** Chronic Kidney Disease; Hemodialysis; Lived Experience; PhysiCAL; Psychological; Social.

#### RESUMEN

La enfermedad renal crónica es un problema emergente de salud pública que afecta al bienestar general de los pacientes. Su prevalencia está aumentando en todo el mundo. La hemodiálisis es la principal modalidad de tratamiento e impone grandes retos a los pacientes. Este estudio explora la experiencia vivida de la calidad de vida de los pacientes sometidos a hemodiálisis. Se utilizó un enfoque fenomenológico entre 12 pacientes sometidos a hemodiálisis para explorar las experiencias de calidad de vida entre mayo de 2022 y diciembre de 2022. Los participantes fueron elegidos intencionadamente. Se utilizó una entrevista semiestructurada para recoger los datos. La entrevista se grabó en vídeo y se transcribió. Se realizó un análisis temático. De las entrevistas surgieron tres temas principales: experiencias físicas, psicológicas y sociales. Se identificaron varios subtemas que iban desde el agotamiento físico hasta la crisis financiera. La exploración del ser interior de los pacientes sometidos a hemodiálisis y la ayuda que se les preste mediante intervenciones psicosociales serán beneficiosas para mejorar su calidad de vida.

**Palabras clave:** Enfermedad Renal Crónica; Hemodiálisis; Experiencia Vivida; PhysiCAL; Psicológica; Social.

## INTRODUCTION

Chronic Kidney Disease (CKD) is a burgeoning global public health concern. It entails a slow decline in the kidneys' ability to filter wastes and extra fluid from the circulation, impacting patients' well-being and necessitating comprehensive management.<sup>(1)</sup>

The global prevalence of kidney failure is escalating rapidly, highlighting the urgent need for attention and intervention on a global scale.<sup>(2)</sup> According to the Global Burden of Disease study, approximately 1,4 million deaths were attributed to CKD worldwide in 2019. This marked a significant 20 % increase from 2010, making it one of the largest rises among the leading causes of death.<sup>(3)</sup>

The prevalence of CKD varies across different regions, with reported rates ranging from less than 1 % to 13 %. However, according to the Kidney Disease Data Center Study conducted by the International Society of Nephrology, the prevalence has been reported as high as 17 %. Approximately 10 % of the Indian population is affected by chronic kidney disease (CKD).<sup>(4)</sup>

CKD can exert adverse effects on patients' physical, mental, emotional, and social well-being, significantly affecting their overall quality of life (QOL). Individuals diagnosed with CKD require renal replacement therapy (RRT) such as hemodialysis, peritoneal dialysis, or transplantation to maintain and extend their life.<sup>(5,6)</sup>

Hemodialysis is still the most widely used form of therapy in the world, with at least 80 % of patients using it in more than 70 % of reporting countries.<sup>(7)</sup> Hemodialysis brings about substantial changes in patients' lives, introducing new patterns and limitations that can lead to complex and altered lifestyles for both patients and their families, ultimately diminishing their quality of life.<sup>(8)</sup> Although hemodialysis can extend life, its complex nature has a negative impact on patients' daily lives and makes them more symptomatic.<sup>(9,10)</sup>

Among the symptoms, the frequently felt are sleep difficulties, peripheral neuropathy, infection, exhaustion, stress, anxiety, and depression, as well as cognitive changes, pain, and erectile dysfunction. Furthermore, it has a significant financial dilemma because of the high cost of dialysis therapy and has an influence on patients' body image due to grafts or fistulas. Their overall symptom load has been compared to those of individuals with advanced cancer.<sup>(11)</sup>

Studies have explored the Quality of Life of patients undergoing Hemodialysis Quantitatively and reported that the quality of Life was low especially physical functioning, psychological, Social and Psychological aspects.<sup>(12,13)</sup> In order to properly handle these physical, psychological, emotional, and spiritual changes, nephrology nurses and other health professionals working in nephrology unit need to understand the lived experiences in the unexplored areas among hemodialysis patients which will improve the quality of care.

Objective of the present study was to explore the lived experience of quality of Life among patients with CKD undergoing Hemodialysis

## METHODOLOGY

This was a qualitative study using an interpretative phenomenological approach used to describe in detail the Quality of life from the perspective of patients who have lived with the illness. Twelve patients with chronic kidney disease undergoing Hemodialysis, with purposive sampling, participated in the study. Patients who were undergoing maintenance Hemodialysis for more than 6 months, above 18 years, had regular hemodialysis attendance and were willing to express their concerns were included in the interview.

The patients were interviewed during dialysis time, while they are stable in the dialysis unit from May 2022 and December 2022. Ethical clearance was obtained from Institutional ethical Committee (No.86/2020/IEC/ACSMCH dt.16.12.2020). Patients were explained the purpose of the study and Informed consent was obtained. Confidentiality was assured.

A semi-structured in-depth interview (face-to-face) was the primary method utilized to gather data and acquire reliable information. The average interview lasted 20 to 25 minutes. Each interview began with generic inquiries and then moved into a relaxed, adaptable approach. The interview was facilitated by a few questions like Tell me your experience since you were started on Dialysis, Difficulties and discomforts experienced after diagnosis of CKD, What are the difficulties and discomforts experienced while on Dialysis? At the same time, a few probing inquiries, like "Could you please explain it more?" or "Can you clarify what you mean with an example?" were used to obtain rich and understandable data. The whole interview was video recorded.

The participants were given the assurance that they could end the interview at any time, and every precaution was taken to make sure they weren't in any emotional harm. The researcher then listened to each recorded interview numerous times, taking into account nonverbal cues, and then wrote down every word verbatim and assigned each interview a number. Thematic Analysis from Max Van Manen's Interpretative Phenomenology was used to analyze the data.

## RESULTS

A total of 12 in-depth interviews were conducted among the hemodialysis patients. Data analysis showed that three main themes namely Physical experience, Psychological experience and Social experience.

## PHYSICAL EXPERIENCE

Patients on hemodialysis frequently experienced range of physical discomforts. The sub-themes of physical experience are Symptoms experienced and treatment commencement, Diagnosis complexities, Dialysis discomforts, Dietary curtailment, and Living in perpetual wakefulness

### *Symptoms and treatment commencement*

The initial symptoms are often ignored by patients which might result in late diagnosis and treatment thereafter. Most of the interviewed patients expressed that they had symptoms which could not relate with Renal failure. Verbatims obtained from Participants well explain this result in the following manner.

The participant number 2 expressed in distress that, *‘Yes, I was taking regular treatment for Hypertension, since I developed swelling and breathing difficulty, after investigations doctor told me that compulsorily I have to do dialysis’*.”

The participant number 8 also had a similar experience and pronounced with tears that, *“When they told there is problem with kidney I thought it will be ok if some treatment is given. At that time I didn’t know that this problem is going to be lifelong and it is going to be like this, Basically about the disease and the symptoms I was having no idea”*.

It is evident from other participants’ statements also (Participants 11 and 12) that they had swelling and breathing difficulty which they didn’t relate with Kidney Failure. Hesitation in accepting the treatment modalities especially Hemodialysis was also expressed by participant 11 in the verbatim *“I was having hard time for six months, It took six months for me to accept to undergo dialysis, could not sit, breathe... then dialysis was the only option”*

### *Diagnosis complexities*

Participants were expressing that they had difficult times at the time of diagnosis of Chronic Kidney disease.

The participant number 2 says with regret, *“I was taking regular treatment and undergone regular investigations. Only during routine investigations it was identified to have CKD. I had mild swelling in the face and mild breathing difficulty”*.

In continuation of this another participant number 4 expressed in innocence how lightly he took the diagnosis of Kidney problem in the verbatim which says, *“When I heard dialysis for the first time, I thought that it would be fine if it is done twice or three times, but when I realized that its going to be life long, I was greatly stressed.”*

Similar experience was shared by another participant Number 5 who gave a pause, took a deep breath and said *“Ah.....It was before 2 years I became very serious suddenly with severe breathlessness and got admitted me in a private hospital ICU and I was recovered and later only I realized about the Kidney disease”*

### *Dialysis discomforts*

As hemodialysis demands patients to be in the dialysis bed for hours together, participants conveyed that it is their utmost difficult part in their disease process.

Participant number 7 expressed that, *“I always have swelling in the abdomen and breathing difficulty also. Unable to lie in the same position, afraid of fistula too”*.

Other participants also shared their physical aches and discomforts while on dialysis. Participant number 10 with a big sigh says that, *“same position is painful. Leg pain cramps, fear of fistula, giddiness low BP, oh.... extremely tired and exhausted”*.

Though difficulty is verbalized by most participants, few say that it is a gift and only during this 3-4 hours, they are able to sleep without breathing difficulty and feel relaxed after dialysis.

### *Dietary curtailment*

All participants voiced their profound sorrow at not being able to eat and drink as they pleased and thought it was quite disgusting. Some even grieved and lamented that while food can be given up, it is very difficult to eliminate water because it is such an essential necessity.

The participant number 3 recalls that, *“I am very much fond of pickles. but now I am not even able to touch. It is a very big loss. Cries... Controlling water is a big challenge for me ”*.

These words were supported by the participant number 4 who also expressed a similar experience *“....One day I wanted to eat Briyani which is my favourite food....little I had, it was spicy...drank lot of water and that’s all. I had severe abdominal pain and breathing difficulty....., came running to Hospital even before the unit was opened....”*. and participant Number 9 also shared *“I used to drink lot of water, I love to eat semi solid, liquid food items, kanji ( Porridge) is my favourite food ....I will take kanji even for all three meals...which I am unable to take even once”*

Though difficulties expressed, few participants also acknowledge that it will be harmful to their health if

restrictions are not followed. Participant number 5, admits that “*Oh My God...only 500 ml of fluid ...for 24 hours including everything....unable to manage especially in Summer. But nothing can be done ....suffered fewer times because of water accumulation in Lungs.*”.

Participant number 12 also acknowledges this who states, “*I used to drink around 4 litres of water now it is very difficult to control the water intake ..... smiles .....Sometimes without family’s knowledge I used to drink water then I realise that it is important for my health .....so I am trying to control water intake. Actually my water restriction is 500 ml but I am not even taking 500 ml ..... only for swallowing tablets*”.

### **Living in Perpetual wakefulness:**

Study participants verbalized that they experienced discomforts during sleeplessness, interrupted sleep patterns. Their world of complete wakefulness was filled with lots of pains and concerns.

The Participant number 3 expressed that, “*Very painful not bothered much about anything feeling that why am I living with no sleep*”. Another Participant in her words expressed that, “*Sleepless nights, only on the days of dialysis I am able to sleep. Not able to do anything, becomes very tired*”.

The patient number 9 recalls that, “*Care of fistula is my concern, no sleep at all. Very distressing to keep awake all night.*”.

These words are supported by the participant number 10 as, “*Not able to sleep, breathing difficulty and having extreme tiredness*”. Almost all participants expressed that their nights are filled with disturbing thoughts and unfulfilled commitments.

## **PSYCHOLOGICAL EXPERIENCE**

The sub- themes of Psychological experience are Emotional turbulence, Guilt and embracing illness and Unrealized aspirations and coping.

### **Emotional turbulence**

Most participants expressed Shock, helpless situation and uncertainty. Voices laden with cries of despair and a sense of hopelessness vividly convey their emotions.

“*Why this to me? Very bad disease, you cannot skip dialysis, and it has changed my whole life. Why God is allowing, Medical science has no alternative for dialysis. I pray that even my enemy should not get the disease*”. (Participant 1)

This idea is well expressed in the following verbatim by participant 4, “*two fistulas were failed and this was the third time. Life is going on, all desires and hopes lost*”.

The patient number 5 echoed that, “*before dialysis and the Kidney Disease are used to be very strong physically and mentally now became very weak mentally also on physically also mentally...feeling so vulnerable,*”.

The participant number 6, young female in eyes full of tears says that, “*I was not able to understand why I had the problem...very upset. My husband chased me out of the house, beating and telling that I am not fit for anything, physically exhausted. Anything can happen any time....this feeling is there always.....cries..... I am worried that my children will be abandoned after my life.....*”.

Participant number 11 also becomes very emotional when she talked about her children as she says “*I have two daughters, only for their sake I want to live*”.

Similar outburst were seen other participants, as Participant number 12 also expressed in broken tone that, “*I was feeling very bad that are very young age I had this problem it was very difficult for me to cope up, .....my heart is heavy,*”. She was almost frustrated.

### **Guilt and Embracing illness:**

Participants expressed that guilt of not taking care of health and expressed difficulties to accept the illness.

Participant number 3 states that, “*.....heartbreaking. I thought it will get Ok with the drug. since dialysis was only the choice or kidney transplantation..... so much of agony and pain I went through, I was diabetic I should have taken care of my diabetes well, should have taken the medicines properly, I have guilt feeling still even after years....*”.

The patient number 9 states that, “*I Very hard to accept the truth. I think I will be better if God takes me above during dialysis..... that is the only prayer I have, cried very difficult unable to manage.....*”.

Participant number 11 states that, “*Accepting that I have kidney failure was a big war in me. Could not believe. After all I have breathing difficulty and swelling, will it be a failure. I was thinking.....finally had to.....*”.

Another participant number 12 regretted that, “*....I took Siddha medicine for infertility just for three months..... doctors are telling maybe that could be the reason for renal failure and also my kidney became small.....now i feel i should have avoided...now....in tears....past is past..... Feeling little*”.



*guilty, I should have been little careful. Checked early”*

He also expresses his accepting and coping with illness as *“I am coming for dialysis regularly....Because of my child who is just few months old, I am getting distracted I am little happy, able to spend my time.”*.

### **Unrealized Aspirations and coping**

Individuals undergoing Hemodialysis face a life where their aspirations remain unrealized, burdened by multitude of unfulfilled desires.

Participant number 9 explained his wishes and worries *“I was upset and worried and I thought it is too early for me to get this disease, I have two children. If I would have got this problem after 5 years, I will be 50 yrs., I would have settled my children’s study and marriage....”*.

Participant number 6 also expressed her inner turmoil of uncertain future with heavy sigh and hopelessness, *“No life, without knowing what to do, i am forced to leave my home by my husband..... I am just moving forward...no place to live, unable to take care of kids, nowhere to go. I have given a petition to district collector for financial assistance to keep a small fruit stall in my area If it is through, even if I get 100 rupees per day , i will manage”*

### **SOCIAL EXPERIENCE**

The sub-themes of Social experiences included Constrained Occupation and Financial necessity, Perceived stigmatization and Family dependency.

#### **Constrained Occupation and financial necessity:**

All participants express their joblessness and the financial struggle they undergo.

Participant number 6 expressed that, *“my husband is an alcoholic; I was going for work and taking care of my two kids. Now, no income for me...only expenses.....just withdrawn...Even to come to dialysis centre I am waiting for free bus and come”*.

Participant 8 expressed that, *“support no one is there, my brother enquires me once in a while. Financially very difficult, little property is there”*. Similar experience of selling the property for the treatment was shared with burden by participant number 9 states who says, *“No support as such. My brother is also having the same problem, here only he is also coming for dialysis. We had some property, we sold it and utilizing that amount for treatment and family”*.

Participant number 10 recalls, *“...without any rest I used to work and supported the family. (Pause ...with tears) Now my life changed upside down.... Getting leg pain, worried if something will happen to my fistula. Not able to stand for long time for make-up and hair do.... ”*.

#### **Perceived Stigmatization:**

Participants express their inability to mingle with the society because of various concerns. Participant number 5 states that, *“I have stopped going out anywhere.....I will not go for any functions..... I used to vomit in front of everybody if I eat in functions, is embarrassing for me so I have stopped going for any family functions, if it all I go I never eat there”*.

Other participants also shared an identical experience of avoiding social gathering. Participant number 9 states that, *“I feel very much disturbed. Not mingling with anybody, no family functions I am able to attend, not able to stay outdoor. My body has become weak. Anyone who sees me will identify that I am sick because, i have become dark and lost weight....swelling all over the body”*.

#### **Family Dependency**

Participants conveyed that due to their illness, they have no option but to depend solely on their family.

Participant number 11 expressed that, *“I was diabetic and Hypertensive, my vision is almost lost and nothing could be done. My children are suffering because of me. Becoming a burden. ....But they are taking care of me well”*.

Support of Children or spouse is treasured by the patients. Participant number 4 said, *“I do very simple things. I can’t lift weights. Husband and children help.”* Participant 5 also expresses the support of his spouse as he says, *“All household and outside work is done by my wife alone ”*.

### **DISCUSSION**

This study tried to explore the extremely burdensome experience of patients undergoing Hemodialysis. Three major themes emerged were physical experience, psychological experience and social experience.

Physical experiences of the participants included range of symptoms experienced, diagnostic complexities they underwent, extreme weakness and sleeplessness. Present finding are coherent with the studies conducted

in different states in India which indicated that the body becomes too weak and experienced variety of symptoms including pain in all parts of the body, particularly their joints, insomnia, hypotension, cramps, and drowsiness following dialysis treatment. They tend to restrict their activities out of concern for fistula failure.<sup>(14,15,16)</sup> Additional aspect of accompaniment in addressing everyday requirements was the family's responsibility to provide proper nutrition.<sup>(17)</sup>

Emotional subtheme seemed to be similar to that of a study conducted in Ethiopia which indicated that participants' expressed aside from sobbing, uncertainty, denial, hopelessness, dread, frustration, and yelling, other emotional reactions discovered through data analysis include emotional ability and the anticipation of bad luck.<sup>(18)</sup>

Guilt and difficulty to accept illness was also reported by few studies as majority of them are unable to accept the illness leaving them anxious and despairing. Remorse over the fact that some of them did not recognize the illness's symptoms at an early stage and that their own behaviors had severely harmed their kidney health.<sup>(14)</sup> Social experience theme seems to find support studies which reported that being alone with existential questions, lacking familial support, and being unable to participate in typical social activities and that hemodialysis patients experience a life filled with several losses. Participants' descriptions of loss ranged from lack of physical stamina to loss of employment and prosperity, feeling dependent on others for financial, physical, or social support as they cope with their sickness.<sup>(8,11)</sup>

## CONCLUSION

The results provide insight into the inner world of patients who are undergoing HD and their QOL experiences. The study disclosed various physical, emotional and social impact of hemodialysis. The new information would be useful for testing non-pharmacological treatments that could improve the quality of life and dignity of persons with HD.

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## CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

## AUTHORSHIP CONTRIBUTION

*Conceptualization:* Parameswari.M, Dr.Hema.V.H, Dr.Seethalakshmi.A, Dr.SathiyaPriya.V

*Data curation:* Parameswari.M

*Formal analysis:* Parameswari.M

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*Methodology:* Parameswari.M, Dr.Hema.V.H, Dr.Seethalakshmi.A, Dr.SathiyaPriya.V

*Resources:* Parameswari.M

*Supervision:* Dr.Hema.V.H, Dr.Seethalakshmi.A, Dr.SathiyaPriya.V

*Validation:* Dr.Hema.V.H, Dr.Seethalakshmi.A, Dr.SathiyaPriya.V

*Drafting - original draft:* Parameswari.M

*Writing - proofreading and editing:* Dr.Hema.V.H, Dr.Seethalakshmi.A, Dr.SathiyaPriya.V