



## A Qualitative Study on Lived Experience of Patients Undergoing Hemodialysis in Selected Hospitals of Moradabad U.P.

### Nursing

**Ms. Saroj L Shah** Msc. Nursing final year, Teerthanker Mahaveer College of Nursing, TMU, Moradabad, U.P.

**Mrs. K. Chithra** Assistant Professor, Teerthanker Mahaveer College of Nursing, TMU, Moradabad, U.P.

### ABSTRACT

**Background:** Chronic kidney disease (CKD) is becoming a major worldwide problem. Chronic illness affects a person physically, emotionally, financially and psychologically. Chronic kidney disease patients need a long term treatment and dependent dialysis for whole life.

**Objective:** To explore the lived experiences of patients undergoing hemodialysis.

**Materials and methods:** Phenomenological design was adapted. Fifteen samples were selected by purposive sampling technique. Semi structured interview had done for 15-20 minutes and data was audio taped.

**Results:** Husserl's method was used to analyzed the data. Eight themes were emerged out Mental Agony, Physical limitation, Family support, Financial burden, Dietary pattern, Mixed feeling towards dialysis machine, Loss of employment and Uncertainty no hope for future.

**Conclusion:** Major problems were raised due to long term treatment. Need to generate knowledge and awareness regarding the chronic kidney disease. An interventional study has to be conduct in future.

### KEYWORDS:

Lived experience, Hemodialysis

**INTRODUCTION:** Chronic kidney disease is the most global issues in health problem. According to world health organization the major global problem of disease were urinary tract infection and kidney disease that leads to approximately 850,000 deaths per year. CKD was 17th most cause of disability and 12th major cause for deaths. 10% of global population influenced with this illness, and mortality rate increased every year because majority of patients didn't afford the cost for treatment. According to global burden disease project of 2010, chronic kidney disease positioned 27th for total number of deaths in 1990, but it will elevated up to 18th in 2010.

According to Indian population based study was figured out that incidence rate of end stage renal disease at 151 and 232 per million population (Modi and Jha 2011). Thus, it approximated that about 55,000 patients on dialysis in India, 10-20% will be growing rate of population on dialysis.

In Moradabad there are no government hospitals for offering hemodialysis treatment in subsidal cost but some private hospitals are there to provide the hemodialysis treatment to patients providing good quality of care but it's too expensive for the patients. The therapy for CKD is expensive and lifelong. At presently in public or private hospitals amount for one dialysis it ranges from 2000 to 3000. Thus, the patient required 8000 to 16000 for a month of dialysis also other expenses for medications. Majority of patients not able to afford injection erythropoietin (1450 per single dose, 26100 for one month). Maintain hemoglobin level they had to take of now, the cost of single dialysis in a private hospital ranges from 2000 to 3000 and hence a person requires 8000 to 16000 for one month dialysis alone whereas they are in need of additional medications. Most of the patients cannot afford the cost of injection Erythropoietin (1450 for single dose, for one month 26100), where they had to take this injection for maintaining hemoglobin level in body. Nurses and other health professionals need to understand the lived experiences of patients on hemodialysis to properly respond to their physical, psychological, emotional and spiritual changes. By gaining these insights, health professionals can develop appropriate nursing responses and improves quality of care being provided to these patients (Polaschek, 2003). Need of the study Due to ongoing hemodialysis changes in their quality of life and impaired functional status of individuals, had affected on the patients lives and in end stages it disturbed physically, financially, family function and emotionally. The quality of life of these patients get disturbed from this disease life treatment and most of them faced disability. Condition of life was affected in dimension of mental, spiritual, physical and social health as individuals experiences in all phases of life. (Fateme Pashaii et al, 2010).

### MATERIALS AND METHODS:

A qualitative research approach used for the study. Phenomenological

design was opted for the study to describe about the lived experiences of patients undergoing hemodialysis.

**Setting:** Teerthanker Mahaveer hospital and research centre and COSMOS Hospital of Moradabad U.P.

**Sample and Sampling technique:** patients diagnosed with CKD and undergoing hemodialysis aged 18-60 year in selected hospital at Moradabad and sample size was fifteen and purposive sampling technique was used.

### Inclusion criteria

- Patients diagnosed with CKD, completed minimum 6 months of undergoing hemodialysis.
- Patients age above 18-60 years.
- Participants who are willing to participate

### Exclusion criteria

- Those who were restless, feeling of fatigue and high blood pressure during dialysis, delirious, serious patients admitted from ICU's, critical patients were excluded from the study.

### INSTRUMENTS:

Information such as age, gender, educational status, marital status, occupational status, family monthly income, reason for dialysis, duration of dialysis and frequency of dialysis and interview session had total six questionnaire prepared by the researcher on the basis of objective of the study. Five experts validate the tools and give their suggestions. Questions were translated into Hindi and back to English. The pretesting was done on five samples at TMMH&RC in dialysis unit on lived experiences of patients undergoing hemodialysis. Semi-structured interview was conducted for 15-20 minutes and recorded for each sample.

### Ethical Consideration

Approval was obtained from Institutional ethical committee. Confidentiality was assured. Written informed consent obtained from participants.

### Data Collection

Data were collected on the month of March 2017. Participants who were willing to participate after the exclusion criteria. Fifteen samples were selected semi structured interview was done. During the time of dialysis the data was collected because before the dialysis patients feel dizziness and fatigue. Dialysis was done for each patients for 4 to 5 hours. The each interview time taken 15-20 min.

### DATA ANALYSIS

Husserl's Method used for data analysis

**Step 1. Bracketing:** The researcher use reproduce her own knowledge to understand condition and experiences to strict on objective, also to represent the in a genuine way.

**Step 2. Intuiting:** In this step researcher had to exposed to the meaning s accounted by the patients about his sufferings in ongoing long term treatment towards experience and got totally involved in it.

**Step 3. Analyzing:** Interviews were recorded and audio taped. Written consent of the participants done. Write out the statement into diary or sheets and then arrange the data systematically. Meaningful statements were emerged out of them, through the statements common themes were carried out . The statements along with theme were categorize to check participants statements match the theme.

**Step 4- Describing:** The results were explained in form of themes, subthemes, theoretical descriptions and their formulated meanings.

**Table 1: Themes and subthemes**

Themes	Sub themes
Mental Agony	<ul style="list-style-type: none"> <li>Struggle to accept illness</li> <li>Guilt of worsening kidney disease</li> </ul>
Physical limitations	<ul style="list-style-type: none"> <li>Variety of symptoms</li> <li>Life centered dialysis</li> </ul>
Family Support	
Financial Burden	
Dietary Pattern	<ul style="list-style-type: none"> <li>No dietary restrictions</li> </ul>
Mixed feelings towards dialysis	
Loss of employment	<ul style="list-style-type: none"> <li>Helpless to do job</li> </ul>
Uncertainty and no hope for future	<ul style="list-style-type: none"> <li>No hope to improve future</li> </ul>

**Theme: Mental Agony**

When I heard about my illness I felt depressed. It was a really shocking moment for me. I prayed to god not to bestow such sufferings even to my enemies as it was going to be very painful for me for rest of my life. I had no other option left but, to be on dialysis. Words are not enough to convey the pain of my illness. (P7, P11, P9, P15) It was very much disheartening for me to be advised for dialysis by the doctor. Kidney had already damaged so nothing can be done to improve my condition. (P 12) Loss of hope nothing can improve their illness represent the negativity about illness. Hearing about the chronic illness and its long term treatment and no hope for cure most of them feel depressed.

**Sub Theme:a) Struggle to accept illness:**

I was shocked to know about my illness for the very first time. It was very much unexpected to me where I couldn't believe it first.(P1, P3, P4, P5) I feel like as if am the most unhappy person in the world. When I heard about the illness I lost my mind, I did not want to live anymore. Dialysis was compulsory in this case as there were no other alternatives.(P6, P10) Most of them are not able to accept the illness that made a drastic change in their health and also effect internally which makes them tensed and hopeless.

**Difficult to believe which is unexpected.**

b) Guilt for worsening kidney disease  
I used to take medicine initially by the doctor's prescription. I believed that medicines could cure my illness. Doctor also advised me about the diet. However, at length it just did not came up to my expectations and it became shoddier.(P2, P13) Feeling of guilt because some of them did not understand the problem of illness in early stage their own actions worsened the kidney health vigorously.

**Theme : Physical Limitation**

I have seen many suffering with the same disease. Therefore, I take it as my destiny and ilm continuing with it. (P13, P15) I had leave my studies in the middle course due to illness. Unable to perform even a single work at my home. Just keep on passing my days with no work at all. My health issues were a bar in the progress of my family obligations.(P5, P9) There is a restriction to the overall activity of the individual and not to do their routine work of daily basis and Some of them limit their work due fear of failure of fistula.

**Sub Theme: a) Variety of symptoms:**

I felt pain all over my body before dialysis. Some activities like standing for a prolonged time and walking even. It leads to a

restlessness , increased blood pressure and difficulty in breathing. (P1, P7, P8, P10, P11) Due to both kidney failure and ongoing dialysis treatment body get too weak and illness causes a variety of symptoms while doing a work among the individuals.

**b) Life centered dialysis**

I can't do my job due to illness. No one is offering job to me due to illness. I feel lot of weakness due to it and at intervals of 2 to 3 days I have to come for dialysis. I never desired to miss the dialysis as it was very difficult to get appointment for the process. In addition, traveling for this entire exercise made me more tired and exhausted.(P2, P3, P4, P12, P14) Dialysis is an important part of life, waiting to get relieve from it.

**Theme : Family Support**

I have five sisters in my family. All have got married. used to came for dialysis alone. Occasionally I was assisted by my brother in law. While I came for dialysis. He was a great support for me.(P 6) I belong to a poor family. I am not able to do anything for them. I am getting weak day by day. They are supporting me at physical and psychological levels. (P4, P11) There is perceived good family support physically, emotionally or psychologically.

**Relatives support helps to continue the treatment.**

**Theme : Financial burden**

A lot of expenses are involved in one dialysis. I had to pay approx. Rs.2500/-. I used to come here two times a week. Which make it Rs. 5000/- a week to spend for this exercise. All were tensed due to expenses as there were other outlays too. I feel helpless, and do not want to continue like this. (P1, P3, P5, P7) I sold my shops and property to bear the expenses of the disease. It just takes all . I feel sad and depressed.(P15, P6) Treatment was too expensive for middle class individual. Hence, other outlay for travel, children education etc.. Need to fulfill the demands that becomes problematic for them due to chronic illness.

Some of them constantly worried about their treatment due to lack of finances and don't want to live.

**Theme: Dietary Pattern**

Doctor told to avoid salt and fluid diet. It is important to follow the diet that maintains health. Therefore, I take care of my health and follow the instructions of specialists.(P2, P4, P8, P11) Some of them feel that adapting the dietary pattern due to illness is effective to maintain the proper health.

**Sub theme: a) No dietary Restrictions**

There is no restriction in my dietary pattern. The most important aspect of my diet was fluid which I went to consume up to six liters a day. Nevertheless, due to the ailment I cannot consume even a half liter a day. (P1, P3, P5) I am not follow the dietary pattern. I used to eat all types of food with no restriction in diet. Why should I followed the diet if i'll m on dialysis.(P9, P10, P12, P15) Most of them not following the dietary pattern they thought being on dialysis is not so important to follow the dietary pattern.

**Theme: Mixed feeling towards dialysis machine**

**Positive feeling**

I felt fatigue, heaviness of body and difficulty in breathing. I felt relaxed. It also removes the excess fluid from the body and reduces the body weight. (P1, P2, P5, P8) Dialysis machine is very important for me... It relieves my pain. However, If I miss the dialysis it causes problems related to sleep, and breathing difficulty.(P3 P4, P15) Negative feeling Initially it felt very disheartening as there were no improvement. I had to undergone for the dialysis after every regular three days. It felt very lethargic on next day of dialysis.(P6, P9) Most of them have positive regard during dialysis because they feel it relives them being on dialysis. Some of them feel that dialysis is not improving their health it make their body lethargic and weak.

**Theme: Loss of employment**

Illness made me leave my studies in the mid of session. I was not able to do a job. It was very hard to manage the job with illness. Dialysis too supplied a very transitory effect as I felt feeble after a day of dialysis.(P1, P2, P5, P9) I left my job due to my illness. I spent my hard earned earnings for treatment. Nonetheless, I found no improvement even after the treatment.(P4) Some of them feel that illness is the major factor that not allows carrying out their job. This illness makes their

health worst where they can't able to perform their activities of daily life.

#### Sub theme: a) Helpless to do job

I want to do job for my family members but my body condition does not allow me to do the daily work. Nobody is offering me job because of my illness. There was a lot of financial problem in my family. I could not support them well due to their disease. (P 6, 9, 10) Most of them are helpless for their family because this illness ruins the working strength where they can't work for a paying job.

#### Theme: Uncertainty & No hope for future

I do not have enough money left to continue the treatment which makes me very uncertain for the future. It is becoming very tough for me to continue in such a stretched condition. (P2, P4, P8). I have made a reservation in AIIMS, Delhi, for finding transplant. It has been six months since the reservation was made. I'm waiting for my turn for the treatment. (P1, P3, P5) They were unpredicted about their future and feel no use of their living. Some of them are unsure about the possibility of kidney transplant.

#### Sub theme: a) No hope to improve future

I had no other option left, but to go for dialysis only. I could not get a kidney donor for my treatment in spite of all my efforts. Hence, I'll be on dialysis for the rest of my life. Moreover, I have changed my mind for the transplant as I have heard of causes having problems after transplantation too. (P 9, P10, P15) Some of them are hopeless not getting donor, dialysis is their life and had nothing to hope for future.

### DISCUSSION

At present study major themes were revealed out from statements of patients themes Mental Agony, Physical limitation, Family support, Financial burden, Dietary pattern, Mixed feeling towards dialysis machine, Loss of employment and Uncertainty no hope for future.

A meta synthesis of phenomenological studies on patients lived experiences were emerged out four major themes such as: feeling of mental and emotional distress, having physical shackle in life, depend on hemodialysis machine and dealing with problems of life.

In this study derived out loss of desire for living and feeling of guilt were closely related with insufficient knowledge regarding prevention and management of chronic renal failure. Same study conducted to explore the lived experience of patient with end stage renal disease (Clarkson and Robinson) highlighted subtheme on education and health management that gaps identified in health care services whereas patients were having inadequate information related to preventive measures that diminish their health.

Physical limitation has emerged out one theme in present study. Findings of qualitative study conducted by Theofilou et.al reported that fatigue is major symptom in post and during dialysis interfere with physical activities. Other study conducted by Jadhav et.al found that pain, loss of appetite were predominant the physical limitations. Study conducted by Sabet, P et.al reported same theme that patients undergoing hemodialysis leads changes in daily activities and travelling.

Family support is one of the important theme emerged out from the study participants. Rohini . T. conducted a study on lived experience of patient undergoing hemodialysis in quality perspective reported in study that support and comfort from husband and relatives in long-term hemodialysis treatment.

Financial burden mostly participants verbalised in the present study. Udaykumar et.al a quantitative study reported that patients on hemodialysis had high socio economic aspect of stress (75.87 ± 6.48) as compared to peritoneal dialysis (39.0 ± 5.55, P<0.001). Jha.V et.al reported that care for chronic kidney disease mostly available in higher hospital. No hierarchy level health system, patients can refer to any hospital. Shortage of public funded specialized hospital patients forces to seek care in private hospital where expenses of treatment is more. Hence, they have to fund for treatment from their resources.

Mixed feeling towards dialysis machine was one of theme highlighted in the present study. Guerrero et.al conducted study on understanding the life experience of people on dialysis highlighted that life depend on dialysis machine for living. Study conducted by Valsaraj et.al reported in study feeling toward dialysis machine had positive regard towards machine and dependency of life in machine. Kaba et.al conducted

study understanding problems of hemodialysis patients in Greece found that machine relieves body and controlling the body, separated self from machine patient's not have control over it.

The present study revealed other theme loss of employment patients loss their job due to chronic illness. Same theme revealed Jadhav, et.al conducted Phenomenological study understanding the experience of stress on initiation of dialysis highlighted on socio economic stress related to loss of employment starting after the dialysis that leads to weakness all over body unable to perform their daily work.

The current study revealed that most of the patients were undecided about future. Krueger L. conducted a study on experience Hmong group a Specific migrant population found weakness, profound unhappiness and uncertainty to participate in family activities that contributed to blues in their living. Feeling of uncertainty and scared related to future treatment kidney transplant and death also analyzed. One study conducted in South Karnataka on lived experience of person undergoing hemodialysis revealed that uncertainty and fear of tomorrow that chronic illness leads to hopelessness that nothing can improve their condition.

### CONCLUSION AND RECOMMENDATIONS

Ten themes emerged out in this study Mental Agony, Physical limitation, Family support, Financial burden, Dietary pattern, Mixed feeling towards dialysis machine, Loss of employment and Uncertainty no hope for future. The detailed descriptions of patients lived experience shows that patients illness altered their life in various aspects of living. More research studies are to generate knowledge in this area and there is need of professional help solve the problems and support patients with this chronic illness. Psycho therapeutic interventional studies can be carried out to improve the conditions of patients. Awareness programmes should be conduct to build up a knowledge regarding prevention and promotion of health other also to develop positive attitude towards patients suffering from Chronic Kidney Disease.

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