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RESEARCH ARTICLE

LIVED-IN EXPERIENCE AND CHALLENGES OF PATIENTS UNDERGOING HEMODIALYSIS – A PHENOMENOLOGICAL APPROACH

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ABSTRACT

Introduction: Cardiovascular **Aim:** To explore the lived-in experience and challenges of patients undergoing hemodialysis. **Design:** A qualitative phenomenological research design was adopted to explore the lived-in experience and challenges of patients undergoing hemodialysis. 10 patients based on predetermined criteria were selected using purposive sampling technique and the data were collected using interview guide which consists of 34 open ended questions. **Results :** The findings of the study revealed the lived-in experience and challenges of patients undergoing hemodialysis. From the data collected, the experience and challenges of patients undergoing hemodialysis were thematically analyzed as physiological experience, experience during dialysis, psychological experience, financial experience, physiological challenges, psychological challenges and financial challenges. **Conclusion:** The research findings identified the lived-in experience and challenges of patients undergoing hemodialysis. By exploration of the lived-in experience and challenges of patients undergoing hemodialysis, the researcher found that this qualitative study can be a foundation stone to conduct further interventional studies for the people who are undergoing hemodialysis.

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INTRODUCTION

Health is the level of functional or metabolic efficiency of a living being. In humans, it is the general condition of a person's mind, body and spirit, usually mean to be free from illness, injury or pain. A disease is an abnormal condition affecting the body of an organism. Human health is influenced by many factors like nutritional, biological, chemical or psychoogical factors. Some diseases are chronic and persist lifelong (V.Seymour,2016). Functional units of kidneys are nephrons. They are composed of a renal corpuscle and a renal tubule. The main functions of nephrons are urine production and excretion of waste products, regulation of electrolytes, serum osmolality and acid base balance, hormone production, secretion and maintenance of glucose homeostasis. Urine production involves filtration of the plasma in renal corpuscle, the secretion of substances to be eliminated into the lumen of renal tubules and the reabsorption of substances within the renal tubules. These processes are regulated by a number of hormones that affect either renal blood flow or the functions of the different transporters across the renal tubules. In addition, there are local mechanisms that regulate renal perfusion and urine osmolality.

The most commonly used measure of renal function is the glomerular filtration rate, which is the volume of primary ultrafiltrate filtered into the Bowman capsule per unit of time (Amboss, 2020). Chronic kidney disease (CKD) is a worldwide health problem and a common non communicable disease. CKD is a gradual and permanent loss of kidney function. Generally, renal diseases progress to a final stage as End Stage Renal Disease (ESRD) and the function is substituted by Renal Replacement Therapy (RRT), Hemodialysis, Peritoneal dialysis or transplantation (Jamison et al., 2016). Dialysis is a form of renal replacement therapy, where the kidney's role of filtration of the blood is supplemented by artificial equipment, which removes excess water, solutes and toxins. Dialysis ensures the maintenance of homeostasis in people experiencing a rapid loss of kidney function, that is acute kidney injury or prolonged, gradual loss that is chronic kidney disease (CKD). It is a measure to tideover acute kidney injury, buy time until a kidney transplant can be carried out or sustain those in eligible for it. (Himani et al. 2023). End stage renal disease (ESRD) can be difficult to manage. Patients may mourn the life they had before diagnosis and struggle to cope with all the new challenges they face.

The top six challenges are weakened immune system, managing appointments, medical bills, dietary restrictions and mental health (K.R.Tifton, 2023). Hemodialysis continues to be the most common mode of therapy worldwide, evidenced by data showing that, in over 70 percent of reporting countries at least 80 percent of patients are on this mode of therapy (Rohini.T et al, 2016). Studying lived experience of CKD patients on hemodialysis will help to improve services by connecting health professionals, researchers, policy-makers to design solutions for encountered problems. Since limited qualitative researches were done previously, this study will be used to fill the gaps by exploring the real lived-in experience of patients on hemodialysis (Hailemariam.T, et al, 2021). Patients with ESRD faces many challenges due to their disease condition which may cause feeling and depressed. Their body image get affected by fistula or grafting for dialysis. Economically they get affected by the high cost of weekly treatments for hemodialysis and sometime admit the emergency department due to the complications. (Saroj.L.S, et al, 2017).

BACKGROUND OF THE STUDY

Chronic kidney disease leading to ESRD is currently a challenge faced by more than 2 million people worldwide, increasing by 5% to 7% annually. The highest incidence of treated ESRD in 2020 was observed in Taiwan (525 per million population), Singapore (366 per million population), the Republic of Korea (355 per million population), Thailand (339 per million population), Japan (307 per million population) and Indonesia (303 per million population) (USRDS, 2020).

AIM: The aim of the study was to explore the experiences and challenges patients undergoing hemodialysis.

RESEARCH QUESTIONS

- What are the experiences of patients undergoing hemodialysis?
- What are the challenges faced by patients undergoing hemodialysis?

METHODS AND METHODOLOGY

Design: The researcher used a qualitative - descriptive phenomenological approach to explore the experience and challenges of patients undergoing hemodialysis. Brief demographic data were gathered before in-depth interviews combining semistructured and open ended questions.

Study setting and recruitment: The study was conducted in the community with the patients who are undergoing hemodialysis in various hospitals. The study was conducted through audio recording from the participants. The study site was the houses of the participants. Purposive sampling was used by the researcher to choose the participants after receiving formal approval from the ethics committee. The participants were chosen from various villages. A total of 10 hemodialysis patients, were chosen for the study. The researcher gave them an explanation and provided them with consent view.

Data collection: A brief self-introduction about the researcher and detailed explanation regarding the purpose of the study

was given to the patients undergoing hemodialysis. The researcher obtained written informed consent from the participants and they were reassured the confidentiality of the responses. Strict ethical principles were followed throughout the process of data collection. The method adopted for the data collection was in-depth interview method. Information was generated individually from all the participants. The researcher collected information regarding demographic variables of patients undergoing hemodialysis used for the study were age, gender, education, occupation, marital status, residence, income, comorbid illness, support system and diet. Clinical variables used for the study were family history of chronic kidney disease, duration of illness, duration of dialysis, frequency of using hemodialysis and presence of symptoms and problems, before the in-depth interview. The researcher conducted a face to face in-depth interview by using interview guide along with hand notes were taken. The researcher asked open ended questions, so the respondent was able to move about freely in their description of experience. The participants revealed their information through story telling method and also the audio call recorder was used to record the information. The researcher had approached the participants in their house. Based on their convenience of all the 10 patients had given appointments to the researcher for their next meeting. Each meeting would last for about one hour to one hour 30 minutes. The interview continued until the experience was fully described and that was confirmed till the last piece of information, the participants could share with the researcher and thus the data saturation was obtained. The researcher achieved saturation of data with maximum of six sittings with each participants.

Ethical consideration: The study was conducted after obtaining ethical approval from the institutional ethics committee of St.Xavier's Catholic College of nursing (Reference Number SXCCN/09/ RDC/IRB/IEC/2023). Anonymity was assured using codes in the analysis and reporting stages. Data were stored in password – protected file on the servers.

Data analysis: After the data collection, the researcher read, listened to the data carefully twice and transcribed the data in English. This was confirmed by peer review method. The researcher avoided premature analysis by immediately analyzing the early interview. The researcher contacted all the participants for clarification of the information. The researcher has maintained files, codes and retrieved data in a system for analysis of the data. The researcher has adopted Colaizzi's method for data analysis.

RESULTS

Themes and patterns: The investigator identified seven themes and their related pattern across interview data from hemodialysis patients.

PHYSIOLOGICAL EXPERIENCE

ESRD etiology

Family history

P3: "I suspect that my family's history might be the cause of my illness."

P4: “Just like me, my brother also faced a similar kidney failure issue.”

Self medication

P2: “Now I suspect that this medicine (pain killer) might have been the cause of my illness.”

Comorbid investigation

Limited water intake

P4: “I suspect that one of the reasons for my illness may be my limited water intake and irregular bathroom habits.”

ESRD awareness

Awareness on ESRD

P2: “When I first heard about dialysis, I did not react strongly because I was not fully aware of the seriousness of my illness.”

Symptom awareness

P1: “If my potassium level increases, I will experience symptoms such as sudden sweating, headaches, and back pain.”

P3: “In the past, when I consumed a lot of fruits to quench my thirst, I noticed that my face would turn reddish due to the increased potassium content in those fruits.”

Physiological impact

P5: “Notable and significant symptoms were the formation of foam in my urine, loss of appetite, swelling in my body and stoppage of urine output.”

P6: “Initially, when I was diagnosed with a kidney issue, I began experiencing various symptoms, such as my entire body feels sluggish and bulging, as well as difficulties and discomfort in performing everyday tasks.”

Illness misperception

P1: “My family initially thought that I was under some sort of curse or haunted by a ghost, which filled me with fear.”

Health seeking behavior

Allopathy treatment

P10: “I did not take any traditional Ayurvedic treatments; I solely relied on allopathic medicines for my condition.”

Alternative treatment

P1: “I tried Ayurvedic medicine for 41 days, hoping for improvement, but unfortunately, my condition worsened during this time, with an increase in my potassium level and a drop in my haemoglobin level.”

Complimentary therapies

P2: “I underwent a full-fledged ayurvedic treatment in Thenthiruperai. However, I also tried Siddha treatment and during that period, my creatinine level significantly increased.”

Activities of daily living

Independent

P2: “I do not have to depend on my family during each dialysis session.”

Dependent

P4: “Most of the time, I rely on my parents for physical assistance when it comes to my dialysis sessions. My mother accompanies me, especially for bathroom needs, as I have difficulty in bending and performing certain tasks on my own.”

Diet

Dietary adaptation

P1: “Nowadays, I eat a variety of foods I like, including items like parotta and biryani, and, to my surprise, it does not negatively affect my health.”

Thirst management

P6: “when I felt very thirsty, I used to eat aval initially. My doctor recommended that I can eat any quantity of aval.”

P8: “I have a preference for ice-cold water, and I have developed the habit of placing an ice cube in my mouth to help manage my thirst effectively.”

Food exchange

P1: “I must admit that sometimes, due to cravings and desires, I have eaten foods that were not on my prescribed diet. I ate foods like bananas or biryani.”

EXPERIENCE DURING DIALYSIS

Awareness during dialysis

Ignorance

P8: “In fact, I even contemplated the idea of refusing treatment altogether, believing that it might be better to die than to endure the treatment.”

Physiological impact

P3: “My first dialysis session came with its share of challenges. My blood pressure dropped significantly, and I felt like I was about to faint.”

Self reflection

Phobia

P9: “During my first dialysis session, I vividly remember seeing numeral surgical knives and blades laid out near me, adding to my anxiety about the impending procedure.”

Anxiety

P3: “I also knew that there is a rare chance of patients passing away during the dialysis process. This fear makes me feel scared and anxious.”

Depression

P1: “My life was filled with sadness and self-pity for about five years, during which I mostly confined myself to my home.”

Health care during dialysis

Satisfaction

P2: “The nurses there take care of everything, including making payments and buying breakfast, so I do not have to depend on my family during each dialysis session.”

P3: “For my dialysis treatment, I found that Hospital in the Nagercoil area provides the best dialysis care. After my dialysis sessions at this Hospital, I genuinely feel healthier.”

PSYCHOLOGICAL EXPERIENCE

Reaction

Attitude towards dialysis

P8: “During diagnosis, I had no understanding of what dialysis means, but I held a preconceived notion that it would be an unpleasant and painful process.”

Attitude towards renal transplantation

P1: “After conducting further research and considering the numerous difficulties faced by transplant patients, I made the decision not to pursue a transplant.”

P3: “My future plan is to undergo a kidney transplant and move on to the next stage of my life. So, I am eagerly awaiting the transplantation.”

Spirituality

P7: “I used to spend a lot of time praying to God. However, I no longer feel inclined to worship, and I have lost faith in Him.”

Inner feelings

Denial

P5: “Upon receiving the report of my diagnosis, my immediate reaction was one of disbelief. Initially, I thought it might be a fraudulent report and did not want to accept it. I decided to seek multiple medical opinions by visiting different hospitals.”

Phobia

P6: “I also worry about the tube possibly coming loose and causing bleeding. So, I keep a constant eye on the tube while receiving dialysis.”

Anxiety

P2: “I would not wish it upon anyone, not even my enemies.”

P4: “I pray that this illness is not inflicted on anyone else.”

Comorbidity

P3: “During my dialysis treatment, I have been dealing with my thyroid problem, which was diagnosed about two weeks into my treatment. It was during that time that I also experienced back pain, and the doctor explained that thyroid issues can lead to bone pain.”

Guilty

P7: “At the moment, I am concerned about my life since I have lost it, and I am also burdened by the fact that I have been unable to work for the past three years.”

FINANCIAL EXPERIENCE

Support system

Family support

P7: “My wife's brother, who lives abroad, sends money monthly for our expenses. Significantly, I have two brothers, but they do not aid or support me financially.”

P10: “My wife's brother is a significant source of support for us. He does coolie work but helps us by purchasing our daily necessities.”

Social exititions

P1: “One of the staff members from the hospital took me to the church and arranged for me to receive a monthly allowance of around ₹2000 to ₹3000.”

LIVED-IN CHALLENGES OF PATIENTS UNDERGOING HEMODIALYSIS

Physiological challenges

Pain

P2: “The pain was truly intense, and it is challenging to adequately convey the intensity; it felt akin to a near-death experience.”

Suffocation

P6: “Before each dialysis session, I often experience feelings of suffocation, and my legs and hands become stiff.”

P9: “Prior to each dialysis session, I often grapple with feelings of suffocation, making it difficult to breathe.”

Muscle cramps

P2: “Throughout the dialysis process, as I lay in one position throughout, I frequently experienced leg and hand cramps.”

Ascitis

P4: “Currently, I experience abdominal swelling, and I am unsure of the cause. The swelling in my stomach began in the second year of starting dialysis treatment.”

Hepatitis

P5: “About a year ago, I got infected with HCV (Hepatitis C Virus) which resulted in severe stomach pain, and I could not eat properly.”

Pleural effusion

P5: “I began to experience breathing difficulties. For this issue, the doctors at the hospital have explained that these difficulties are often due to the accumulation of water in the lungs.”

Other complication

P8: “I have to lie in bed continuously for four hours during each session, which is quite challenging.”

P10: “The initial dialysis through my neck had some downsides, such as frequent colds and fevers, which made it quite challenging. Sometimes I go for a walk outside my house, although these days it is very sunny and I get thirsty quickly.”

Activities of daily living

P3: “In the first six to seven months, I greatly relied on assistance for various tasks and found it challenging to move from one place to another.”

Psychological challenges

Avoidance

P4: “After my illness, I stopped participating in family functions and events.”

Depression

P4: “Especially when people notice my swollen stomach and inquire about how many months it is been far for pregnancy, it is painful and distressing. Recently, I have found myself distressed, contemplating why my life has been reduced to confinement within four walls.”

Life adaptation

P1: “I believe that everything can change, and I want to help others as much as I can. Despite the struggles I have faced, I have faith that things will improve, and I will get better. I believe in the possibility of change and a brighter future.”

Body image changes

P5: “In terms of my physical appearance, I feel there has been no growth or improvement. During beginning days of dialysis, I have lost a considerable amount of strength, and despite my efforts, I have not been able to regain it”

Guilty

P10: “My primary concern is how to provide money for my family in this condition, as I am unable to work. I am deeply concerned about how I will repay him.”

Denial

P1: “Then the doctors strongly recommended immediate dialysis, but I initially refused and went to Chennai.”

Wish to die

P1: “I felt overwhelmed and had thoughts of despair, questioning why I should continue living such a challenging life.”

P4: “I decide that when my time comes, I will leave the world, but until then I will live life to the fullest, including enjoying the foods I desire.”

Financial challenges

Transportation to dialysis unit

P5: “During covid period, we had to rely on car for transportation, which added to our financial burdens.”

Education of children

P10: My primary concern is how to provide money for my family in this condition as I am unable to work. I worry about how I will support my children's education, especially when they go to college. Even though I talk openly with people, these worries weigh heavily on my mind.

Support system

P6: “We received support for my youngest daughter's education fees from a church.”

Other family expenses

P3: “Due to financial difficulties, my mother had to stop her dialysis treatment and stay at home. My mother lived for five years on dialysis treatment, while my elder sister survived for six years. After being diagnosed with this illness and unable to work, I could not pay my loan obligations. This unfortunate turn of events resulted in us losing our house because we could not make the mortgage payments. We also had to sell our car due to financial difficulties.”

DISCUSSION

The study aimed to explore the experience and challenges of patients undergoing hemodialysis. From the data collected, the experience and challenges of patients undergoing hemodialysis were thematically analyzed as physiological experience like disease etiology are family history, self-medication, co-morbid investigation, limited water intake. Disease awareness are awareness on CKD, symptom awareness, physiological impact, illness misperception, health seeking behaviour are allopathy treatment, alternative medicine, complimentary therapies, Activities of daily living

are dependent, independent and Dietary experience are dietary adaptation, thurst management and food exchange. Experience during dialysis like awareness on dialysis are ignorance, physiological impact, self-reflection are phobia, anxiety, depression and Health care during dialysis is satisfaction. Psychological experience like reactions are attitude towards dialysis, attitude towards renal transplantation, spirituality and inner feelings are denial, phobia, anxiety, comorbidity and guilty. Financial experience like support system are family support and social exitutions. Physiological challenges are pain, suffocation, muscle cramps, ascites, hepatitis, pleural effusion, other complication and activities of daily living. Psychological challenges are avoidance, depression, life style adaptation, body image changes, guilty, denial and wish to die. Financial challenges are transportation to dialysis unit, education of children, support system and other family expenses.

The above findings were supported by the following studies

Hailemariam.T, etal (2021) conducted a qualitative study on lived-in experiences of patients with chronic kidney disease receiving hemodialysis. A phenomenological design and purposive sampling technique was used. Semi-structured interview had done for 15-20 minutes among 12 participants and data was audio taped. In this study, six major themes were emerged such as the seriousness of the disease, challenges to get hemodialysis, financial constraint, restricted life, feeling of dependency and psychological impacts.

LIMITATIONS

- The researcher had little difficulty in getting co-operation from the participants for the interview since it was a new approach to explore the experience and challenges.
- The researcher had difficulty in conducting interview in the home setting.

CONCLUSION

The findings of the current study provide important insights into the lived experiences and challenges of hemodialysis patient. Physiological, emotional and financial burden of ongoing hemodialysis treatment drastically changes the lives of patients with end stage renal disease and their families. Further, most patients receiving hemodialysis lost their job due to the time-consuming nature of hemodialysis and associated physical side effects. However, some patients could continue with their job, earn an income and live independently when they receive adequate support. The findings of study indicate patient's experiences related to receive hemodialysis varied and were influenced by patient's thought about procedure and other individual factors. Therefore, hemodialysis patient need more care and psychological support throughout the life.

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