

CAPTURING THE PHENOMENOLOGICAL PERSPECTIVE OF PATIENTS WITH CHRONIC KIDNEY DISEASE UNDERGOING HEMODIALYSIS IN GUJRAT, PAKISTAN

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ABSTRACT

Chronic kidney disease is becoming more prevalent and causing major health issues worldwide. Hemodialysis is most commonly used to treat chronic kidney disease. Even though it prolongs life, the complicated nature of the treatment process affects patients' normal lives and causes mental health problems. A qualitative method with a phenomenological approach was used in the current study. Data were collected by conducting the semi-structured interview with 10 participants selected through purposive sampling from 2 (1 public & 1 private) Hospitals in Gujrat, Pakistan. Following data collection, verbatim transcripts were converted into themes using the Braun and Clarke (2006) thematic analysis technique. Three major themes about the effect of illness emerged from the narrative of participants in this study: (1) Uncertainty, (2) Impact, (3) Dependency. The results shed light on the experiences of hemodialysis patients, who depend heavily on strong social, familial, and societal support systems to prevent feelings of loneliness, helplessness, and depression. Health professionals can use the study's findings to enhance the standard of care and help patients receiving hemodialysis live better lives.

Keywords: Hemodialysis; Kidney failure; Patients; Phenomenology, Pakistan.

INTRODUCTION

Chronic kidney failure is one of the major health issues facing the world today (Luyckx, Tonelli, & Stanifer, 2018). Every year, the prevalence of the disease has been increasing. In Pakistan, the prevalence of chronic kidney failure is 23% (Hasan, Sutradhar, Gupta & Sarker, 2018). Chronic kidney failure disease (CKD) is a progressive loss of kidney function that is incurable (irreversible), occurs over time, and is permanent. CKD develops gradually over time, which can be monthly or even yearly, and it cannot be cured. If patients receive treatment on a regular basis, kidney function damage may be prevented (Vaidya & Aedula, 2021). Hemodialysis and kidney transplantation are the two treatments for kidney failure. A kidney transplant is the best treatment option for end-stage kidney failure because it can reverse all types of deterioration of kidney function (Hryniwiecka et al., 2020). Hemodialysis is a common treatment for CKD patients whose kidney function has deteriorated because kidney transplantation, the first line of treatment, is still limited by a number of factors, including the lack of kidney donors, the complexity of the operation, and the need for post-operative care (Nurani & Mariyanti, 2013). Hemodialysis is a form of routine blood cleaning used to maintain quality of life and extend survival for people with acute and chronic kidney disease. It involves using a machine called a dialyzer to remove excessive substances from the body's blood (Murdeswar & Anjum, 2020).

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Hemodialysis must be performed for 12–15 hours per week, or at least 3–4 hours per treatment (Nurani & Mariyanti, 2013). Patients who receive hemodialysis therapy may experience improved quality of life and less stress (Gerasimoula et al., 2015). Patients who receive hemodialysis experience physiological side effects of dialysis like Hypotension, chest pain, nausea, vomiting, and dialysis stability disruptions like convulsion, pain, and muscle cramps (Murdeswar & Anjum, 2020).

Although hemodialysis extends patients' lives, it also places many restrictions on them that could cause economic, social, psychological, and physical problems. It may also be the main factor contributing to the patient's hopelessness, low self-esteem, anxiety, and other mental health issues. Many patients go through a state of conflict between being dependent on others and the hemodialysis machine and wanting to be independent, which has an impact on their relationships with the people in their lives who matter most (Elhadad., Ragab, & Atia, 2020). The social effects of this illness and hemodialysis include issues with the economy, employment, and social interaction. In addition, issues like exhaustion, infertility, sexual dysfunction, abnormalities of the bones, anemia, cardiovascular issues, and gastrointestinal issues lead to frequent hospitalizations, which can result in mental disorders and a higher mortality rate. For patients and their families, chronic renal disease and hemodialysis present a variety of psychological, social, cultural, and spiritual difficulties (Yaqoob et al., 2020)

Studying the lived experiences of CKD patients on hemodialysis will help to improve services by bringing together health professionals, researchers, and policymakers to design solutions to problems that arise due to kidney problems and during dialysis. Because there has been no qualitative study as per researcher knowledge has been conducted regarding the lived experience of patients undergoing dialysis in Pakistan. Therefore, this study investigated the lived experiences of CKD patients receiving hemodialysis, in Kharian and Gujrat, Punjab, Pakistan to fill the gaps.

Research Question

- a) What are the lived experiences of the patients with chronic kidney disease Undergoing Hemodialysis?

REVIEW OF LITERATURE

Manookian et al. (2022) used Heideggerian hermeneutic phenomenology to investigate the experience of living with end-stage renal disease in Ghana. Thirteen people were interviewed, and five key themes emerged: spiritual turmoil, living in uncertainty, pain and dissatisfaction stern fortification, and changed roles and positions.

Tadesse et al. (2021) evaluated the lives of chronic renal illness hemodialysis patients in Ethiopia. Twelve people were questioned, and six major themes emerged: the gravity of the condition, difficulty receiving hemodialysis, monetary difficulties, a constrained existence, feelings of dependency, and psychological repercussions.

The hardship endured by patients receiving continuous dialysis for end-stage renal failure was investigated in a study conducted in Malaysia by Beng et al. in 2019. Four categories of suffering: physical suffering, psychological suffering, social suffering, and spiritual suffering—were identified among the 19 participants who were interviewed.

Jarial and George (2019) conducted a qualitative study with hemodialysis patients in India. Nine themes and 38 subthemes were found after interviews with eight participants, including physical effects, perspectives on the disease and dialysis, family, psychological, social, and spiritual care services, dietary restrictions, communication issues, religious beliefs, and monetary and employment consequences.

Shahgholian and Yousefi (2018) assessed the care concepts and real-world experiences of Iranian hemodialysis patients. Four primary themes emerged from the interviews with 17 patients: empathy, companionship in doing everyday tasks, social support and concern, and high-quality dialysis.

RESEARCH METHODOLOGY

A phenomenological qualitative study was conducted from May 2022 to Sep 2022 in 2 hemodialysis units (1 public & 1 private) in Gujrat, Pakistan. Phenomenology is a method of inquiry that focuses on examining phenomena from the viewpoint of individuals who have experienced them to capture their essence. Phenomenology's objective is to explain the significance of this experience in terms of what was experienced and how it was experienced (Teherani et al., 2015). The purposive sampling technique was used to select the sample for the current study. Purposive sampling, a method frequently utilized in

phenomenological research, was used to gather comprehensive, detailed information from every individual. In purposive sampling, people are chosen based on the expertise they have in particular areas (Ames, Glenton & Lewin, 2019). The sample comprised 10 patients with chronic kidney disease undergoing dialysis ages ranging from 30 to 55 years from Gujrat, Pakistan. Participants who were diagnosed with Chronic kidney failure disease and were undergoing hemodialysis from last year, and were willing to participate were included in the study. Participants with mental and physical ailments were excluded from the current study.

Data were gathered using a semi-structured interview. Semi-structured interviews are used when a researcher wants to collect qualitative, unstructured data, delve deeply into sensitive or sometimes personal topics or examine the participant's thoughts, feelings, and beliefs about a particular subject DeJonckheere & Vaughn, 2019). Before conducting a semi-structured interview guide was developed by reviewing the literature, in the Urdu Language. It consisted of open-ended questions that were related to the patient's experience of having renal failure and undergoing dialysis.

Firstly, approval from the hospital authority was obtained for conducting interviews with the patients. Before conducting the interview, patients were briefed about the study and its purpose. Written permission was obtained from the participants, and they were informed about the confidentiality of the participants and data. The interviews were conducted in the companion's waiting area in the hemodialysis wards of the hospitals in Gujrat, Pakistan, before their dialysis procedure. Interviews were conducted in the participant's native languages of Urdu and Punjabi. This approach aided the researcher in establishing rapport with participants and allowing them to focus on the interview session without distraction. Participants were asked questions using the interview guide. Each interview began with rapport building and was followed by a comfortable and flexible format. The interview was guided by a few open-ended questions. Could you tell me about your illness experiences? How is your dialysis treatment going? How has this illness affected your mental health? Can you tell me about your experience with dialysis? Is there anything about hemodialysis or your treatment that you find difficult? How has your personal life changed since being diagnosed with kidney failure? How does dialysis affect your daily life? How has your condition and treatment affected your family? Simultaneously, some probing questions such as "Could you please explain it more?" or "Can you clarify what you mean with an example?" were asked to obtain a rich and detailed perspective. All participants voiced their opinions and shared their ideas about their experiences, and each question was thoroughly discussed. On average, the interview sessions lasted from 45 minutes to an hour and were audio-recorded with the participant's permission. In the end, the participants were thanked for their cooperation and participation

Ethical Considerations

The researcher upheld the ethical standards of informed consent and confidentiality throughout the research. The participants in the research study were given complete information about the research topics, goals, and outcomes. It was explicitly stated that if any discomfort takes place in the research process, the participant could withdraw from the study at any time. Participants were not required to reveal their identities; they were given ID numbers. They were referred to P1, P2, and so on instead of their names to maintain confidentiality. The researcher tried to maintain ethical standards to protect participants from physical, psychological, and social harm related to the research process.

DATA ANALYSIS AND RESULTS

This study was conducted on 10 patients with Chronic kidney failure disease on dialysis ranging in age from 30 to 55 years old from Gujrat, Pakistan. The majority of the participants were females, were married, living in rural areas have education below intermediate, and had less than 5 years of history of illness and dialysis treatment.

Via thematic analysis of interviews, 3 categories were extracted to explain the lived experience of patients undergoing hemodialysis by using Braun and Clarke's (2006) six-step analytical approach (Table 1). These steps were Familiarizing with Data, Coding, Searching for Themes, Reviewing Themes, Defining Themes, and Reporting. The 3 main themes that emerged from the participant's narratives were Uncertainty, Impact and Dependency.

Table 1: Summary of themes and Subthemes

Themes	Subthemes
Uncertainty	Future Uncertainty Uncertainty about quality of life
Impact	Physical Psychological Financial Family and Social Life
Dependency	Dependency on Hemodialysis Dependency on Others

Theme 1- Uncertainty

Uncertainty The study's participants' experiences revealed uncertainty. One of the major themes in the phenomena of hemodialysis is uncertainty, which comprises two subthemes of future uncertainty and Life uncertainty.

1. Future Uncertainty

Uncertainty is a crucial element in chronic illnesses. The participants stated that they are in a situation of uncertainty regarding the future because they do not know whether the treatment helps them to live a normal life or whether they remain dependent on hemodialysis.

Extract 1 "We don't know whether we're getting better or not, ". I've been told that I'm improving. But I know whether I am or not. What is going on, we only have dialysis."(P1)

Participants reported that when they observed no change during treatment, they become hopeless and the fear of uncertainty overcomes the hopes they get during dialysis. Uncertainty about treatment outcomes and disease progression inculcated fear of death in the minds of most patients.

2. Life Uncertainty

The participants reported that they were left in an unclear situation and are unable to think about their life goals and dreams because now they do not know where life will take them.

As Participant 10 said that *"I don't know what will happen in the future...At this time I am blank sometimes I thought I will be recovered soon and live a normal life and at the same time, I start thinking about my death. Can you understand how painful it is to live in a situation between life and death?"(P10)*

Most of them reported that every time they visit the dialysis ward they were scared because they thought that they are at the last stage of their life and soon they be no more. They said it's very stressful and painful for them to think about death every second of life they have. They are in continuous fear because of the uncertainty of life. The participants' narratives show that, in addition to their disease and treatment, they are stressed due to a lack of hope about life and a fear of death. They reported feelings of shock and fear and being in a state of great uncertainty.

Theme 2- Impact

The second major theme was the Impact which further has 4 subthemes that describes the physical, psychological, financial, family and social impact of dialysis.

1. Physical Impact

During the interview, the majority of participants stated that they experienced physical symptoms as a result of dialysis. They also expressed their concerns about the physical pain and discomfort they experience during dialysis. All participants reported fatigue, joint pain, chest pain, drowsiness, hypotension, dyspnea, and tiredness in general. Most of them reported that they are generally unable to perform daily activities after dialysis. As one participant said that

"I trip over after two steps and fall on the ground. My everyday tasks are impossible for me. The Creatinine level was 11, therefore I can hardly move." "...when I have dialysis, I get dyspnea and chest pain, my legs did not support me, and I often fell."(P10)

Participants' narratives also revealed that poor sleep quality was caused not only by physical factors like Chronic kidney failure disease symptoms and treatment but also by psychological factors like significant worry after diagnosis.

As participant 4 stated that *"For several nights, I was unable to sleep. Every night, I would instinctively wake up every two to three hours to think about my disease and its consequences. It is an*

awful thing. I couldn't stop thinking about it at night. It's dreadful since the same thing kept happening day and night, keeping me awake" (P4)

The participants' narratives show that, while dialysis helps them fight their disease, it has an impact on their well-being and quality of life.

2. Psychological Impact

The participants revealed that they experienced a wide range of emotions in reaction to their illness and dialysis treatment, including depression, anger, frustration, sadness, and worry which affect their mental health. The majority of them claimed that after learning about the severity of the condition and the prolonged treatment, they were in shock and depression. As one participant reported that

"I experienced depression after learning about my condition. It was a truly disturbing experience for me. Words cannot express the agony of my condition." (P1)

They revealed that it was challenging to accept the suffering brought on by their illnesses and treatments. Due to their suffering, many people felt helpless and wanted to pass away sooner. The participants claimed that learning about the chronic condition, its prolonged treatments, and the lack of knowledge about it made them feel hopeless.

"At first, I had no idea what dialysis was. So, when I go for dialysis, I feel hopeless" (P7)

The participants' narratives show that besides the disease and treatment, they were also experiencing a lot of psychological issues which affected their mental health and psychological well-being.

3. Financial Impact

Participants expressed their concern about the financial difficulties they are experiencing as a result of their illness and its costly treatment under this theme. Participants perceived dialysis treatment, medication, and transportation costs to be a significant financial burden. The loss of employment exacerbated the financial problems.

Participants struggle financially and cannot access hemodialysis services as hemodialysis is an expensive form of treatment. Due to budgetary limitations, the majority of participants reduced the frequency of hemodialysis services they received within a week and also typically ignored additional recommended supporting medications.

"I get hemodialysis once a week due to the cost of the treatment." My family was unable to contribute 2-3 times the hemodialysis charge, and I was constantly concerned about the cost, which saddened me." (P1)

One of the primary reasons participants reported financial burden was job loss or change as a result of their illness. The participants' stories demonstrate how dialysis and kidney failure has impacted their ability to work. As a result, the majority of the participants have left their previous jobs. Furthermore, some of them have started another job that allows them to work around their dialysis treatment schedule, while others have completely stopped working. They are having a lot of financial problems as a result of these circumstances. They stated that they wanted to work for themselves and their families, but their physical condition prevented them from doing so. The financial burden is even more for the participants that were the only earning member of the family.

Participants also revealed that the disease and treatment process had cost them everything they had worked for over the years. Most participants sell their available assets (such as a goat, an ox, a house, or a car) to pay for their treatment; others borrow or beg from family, relatives, and/or others. This demonstrates the high cost of the treatment process.

"I have no assets left in my possession." Even I sold my car. Because of the disease, I lost all of my properties. Still, I'm surviving on my own for the time being, but in the future, I'm afraid of becoming dependent on others, which is the most I hate in my life." (P8)

Most participants feel guilty because they believe that because of their illness and treatment, the needs of other family members are not being met. They reported that the most difficult thing for them is to see their family members suffer as a result of their conditions.

Do you know what's heartbreaking? When my wife refuses to fulfill my child's wishes to save money for my medical care. AHHH, that hurts worse than the illness itself.

The participants also complained about the hospital's lack of facilities and requested the government to take steps to improve the facilities and make treatment less expensive so that everyone, rich or poor, could benefit from it.

"For poor people like me...we can't get treatment all the time because we can't afford it, but if the government takes steps to make it more affordable, perhaps a lot of lives can be saved." (P2)

The participant's narratives showed that they believe that the treatment was not that difficult but the hardest part is the financial instability that they encounter during their treatment that makes it hard for them. They are mostly stressed about their financial conditions and being burdened on a family financially.

4. Impact on family and Social Life

In this theme, participants discussed how their family life and social life are impacted by their illness and its treatment. They discussed how their illness had impacted their relationship with their spouse. The majority of participants stated that it is difficult for them to devote time to their spouses due to their illness and dialysis. They are unable to spend time with each other as they did prior to the disorder, and they believe that their relationship is suffering as a result.

"I don't even have time for my husband because I have to go there for dialysis and then I don't have any energy left to sit and talk like we used to" (P3).

Furthermore, participants, particularly females, were depressed because they spent so much time worrying about their illness and its treatment. As a result, they have less time to devote to their children. The male interviewees reported that their wives have difficulty managing their time for their children because they are so busy caring for them.

"She pays more attention to me than to my children. " She has completely dedicated herself to looking after me, but in doing so, she has neglected my children. You sacrifice others in order to save one's life" (P8).

They also stated that their relationships with other family members and friends have suffered as a result of their inability to give proper time to them. They rarely visit them, and when they do, they are unable to provide proper company due to their health condition. As a result, other family members and friends no longer visit or invite them to their homes. And sometimes their family members are affected as well because they are so preoccupied with caring for them that their social life also suffers as a result.

My family and friends rarely come to my house because it is difficult for me to devote enough time to them." (P7)

More than half of the participants said they didn't have a social life; they couldn't go out beyond their needs from home and enjoy life as they did. They said that now they limited their social contact and want to be isolated at home. They reported that due to their illness and dialysis, they become so frustrated and irritated they don't want to become part of social gatherings or to meet people. Because they thought that people looked at them with pity due to their poor health condition and dependence on dialysis and this is unbearable for them. That's why the majority of them don't want to socialize.

"For me, it is unacceptable that people looked at me with pity...That's why I prefer not to go outside and meet people. I just want to be in my room alone." (P1)

However, few of them state that they wish to live a life as they did before illness and dialysis. They love to visit their friends and family because in this way their attention diverts from their illness and they enjoy life for some time.

"They (Friends) made me laugh. We share memories of good times. And for that period of time, I forget about what am going through. So, for me, they are a blessing" (P9)

Participants' narratives reflected their experiences with illness and how it affected their family and social life. The majority of respondents in this study stated that due to their illness, all other aspects of their lives had been put on hold. Furthermore, they also stated that their relationships with their families and society have suffered a lot.

Theme 3- Dependency

This theme highlights how dependent the participants are on their families and the dialysis machine.

1. Dependency on Hemodialysis

Most participants believed that they were totally dependent on the machine. The participants claimed that because they must get hemodialysis multiple times each week, they are dependent on it. They stated that, although dialysis relieves their pain and gives them hope for the future but being continuously dependent on it is distressing. They said that before their illness and undergoing dialysis they were free birds they do whatever they want to do and go wherever they want to go but now they are tied to a

machine and without it, they cannot survive and it is the most painful experience ever they have. As one of them stated that

“Normally, this is a good thing, because it removes that unbearable pain... and gives me hope of survival. However, it hurts a lot to imagine my life being suspended on a machine.” (P4).

Another participant reported, *“I’m tied to here (hospital) and tied to this machine and it, unfortunately, runs my life” (P7).*

2. Dependency on others

Almost all of the participants mentioned their dependency on others for their needs. They said that they are dependent on their family for their social, financial, and physical needs. Many of them relied on family members for mobility and transportation. They were distressed because they were unable to perform basic daily activities without the help of others, as a result, causing a burden on their loved ones. They said that it was difficult for them to witness the stress and exhaustion of their family members who tried to accommodate their needs. They expressed their deep concern about the heavy burden they placed on their family member as a result of their illness and treatment.

As one of the male participants stated *“The problem is that my wife is the sole breadwinner. She has to leave early in the morning and return late at night. She is already exhausted. So, I’m concerned that if she collapses, who will look after the rest of us? (P7)*

The participants' narratives show that their dependency on the machine and others made them feel powerless and helpless. Although they are grateful that the machine and others helping them for coping with the disease. But the state of being continuously dependent on others and not being able to do anything freely is distressing for them.

DISCUSSION

The patients undergoing dialysis faced a lot of physical, social, and psychological issues. Uncertainty, Physical Impact, Psychological Impact, Dependency, Financial Challenges, and Impact on Family and Social Life were the main themes that emerged from the participant's narratives.

In Iran, a qualitative study was conducted with elderly patients undergoing dialysis and the results showed that patients lack optimism for the future and fear losing their lives. The participants felt they had no future because of the severity of living a hemodialysis-dependent life. They experience shock, fear, and a great deal of uncertainty (Sahaf et al., 2017). Another study on hemodialysis patients in Thailand also found that participants described themselves as unpredictable, uncertain, reluctant, and doubtful about their lives (Chiaranai, 2015). They also expressed concern about an uncertain future which also supported the current finding. The present study results also confirmed those in the above studies.

Results of a Phenomenological study in Greece showed the physical impact of dialysis on patients. The majority of participants in the study experienced physical impairment from their dialysis because of these symptoms, they were unable to perform their daily tasks (Theofilou, Synodinou, & Panagiotak, 2013). This study confirms the results of the present study and according to patients they experience physical pain and discomfort by dialysis which is also supported by a study by another researcher carried out in Egypt that found that long-term hemodialysis patients frequently experience chronic pain (Ghonemy et al., 2016).

The result of a study conducted on Kidney patients in Singapore reported a high prevalence of psychological disorders among patients with kidney failure disease (Goh & Griv, 2018). Similarly, stress, anxiety, and depression are highly prevalent among patients, according to a previous Iranian study that looked at the prevalence of psychological symptoms in dialysis patients (Senmar et al., 2020). Anger, frustration, sadness, fear, and worry were the most prevalent emotional responses in our study. Similar findings were discovered in Malaysian kidney patients undergoing dialysis who experienced the same psychological issues (Beng et al., 2019).

Results of one study showed that patients are completely dependent on the dialysis machine and others as a result of their illness and dialysis. According to the participant's narratives, they felt helpless and powerless because of their reliance on the machine and other people. Despite the fact that they appreciate the assistance of the machine and others in coping with the illness. However, the constant dependence on others and lack of freedom to do anything for themselves are distressing for them. Studies carried out in Iran also lend support to the current study theme of dependency by reporting

that participants who undergo dialysis experienced multi-level dependence on monetary, physical, and social support as well as the hemodialysis machine (Shahgholian, & Yousefi, 2018)

A study on the lived experience of patients with dialysis in India also reported financial stress as one of the major themes in their results which is consistent with the financial challenges theme of the current study. Under this theme, patients shared their worries about the financial struggles they are going through as a result of their illness and expensive treatment. The results are also supported by a study on dialysis patients in Australia which reported patients' inability to work while undergoing dialysis and increased financial burden (Scholes-Robertson et al., 2022)

The last theme reflects how the participant's disease and its treatment affect their family and social life. Participants' stories described their battles with illness and how they affected their relationships with family and friends. The majority of study participants claimed that their illness had forced them to put all other facets of their lives on hold. They added that their interactions with their families and the community had suffered greatly. They felt like a burden on their family and society. The current study is supported by a study in Greece with dialysis patients which reported that due to dialysis the social life of patients had been greatly affected and most of them feel socially isolated and burdened on their families (Gerogianni et al., 2016)

STRENGTHS AND LIMITATIONS

The most significant strength of this research is that, to the best of the researcher's knowledge, it is the first qualitative study of Chronic Kidney Disease Patients Undergoing Hemodialysis in Gujrat, Punjab, Pakistan. Furthermore, this study demonstrates the difficulties faced by dialysis patients and the effects of dialysis on their lives in the context of Pakistani culture. The study's limitation is the difference in participant ratios based on gender. Male participants were outnumbered by females. Furthermore, because the sample was limited to only one city of Pakistan, the results cannot be generalized.

IMPLICATIONS AND RECOMMENDATIONS

The experts from various medical and care groups, such as doctors and nurses, can better recognize and address their psychological, physical, and social needs and develop an effective plan for them by learning about the experiences of those who are receiving dialysis.

CONCLUSION

Patients receiving hemodialysis are in a vulnerable situation and have a limited lifespan. Because of their fear, they are unable to make sound life plans. In order to reduce their worries, they must be informed about the treatment and the future. Healthcare providers can decrease uncertainty and help patients transition from fear of the disease and its treatment to acceptance of it, thus improving their quality of life. It has several implications for patients their caregivers and health specialist. Health specialists and other medical groups can better assist and plan for patients receiving hemodialysis when they are aware of their issues.

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