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Lived Experiences of Hemodialysis Patients in the Kingdom of Saudi Arabia: A Phenomenological Study

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A B S T R A C T

Hemodialysis is a life-sustaining and life-changing experience. This study employed a qualitative phenomenological approach to explore the experiences of hemodialysis patients in the Kingdom of Saudi Arabia. Using purposive sampling, 20 participants were interviewed face-to-face after obtaining informed consent. To enhance rigor and trustworthiness, prolonged engagement, member checking, detailed descriptions, and audit trails were observed. Further, Cresswell's interpretative design was utilized to interpret and analyze results. This study reveals hemodialysis patients' experiences, challenges, and coping strategies. Two main themes emerged from the key findings: impacts on the mental well-being of hospitalization, patient satisfaction with the care received in the hospital, and the importance of coordinated care. Personal experiences would convey that hemodialysis was considered an artificial kidney and filter, which is critically important but laborious and challenging in necessity and impacts life quality. The challenges faced by patients were laid out as their mental well-being, such as depression and anxiety, and financial constraints. In controlling these struggles, patients entrust themselves with several strategies, including obeying the generated instructions from their therapists, leading a healthy life by exercising, and learning about their illness. There was also a great need for mental strength, acceptance, and support from both family and friends and, apart from the above, engaging in physical therapy to bring back the sense of normalcy and well-being. Overall, this profound understanding will point out more improvements in the systems of care and support given to patients.

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R E S U M O

A hemodiálise é uma experiência que sustenta a vida e a transforma. Este estudo adotou uma abordagem fenomenológica qualitativa para explorar as experiências de pacientes em hemodiálise no Reino da Arábia Saudita. Utilizando uma amostragem intencional, 20 participantes foram entrevistados presencialmente após a obtenção do consentimento livre e esclarecido. Para assegurar o rigor e a confiabilidade, foram adotados procedimentos como envolvimento prolongado, validação pelos participantes (*member checking*), descrições detalhadas e trilhas de auditoria. Além disso, utilizou-se o modelo interpretativo de Creswell para a análise e interpretação dos resultados. O estudo revela as experiências, os desafios e as estratégias de enfrentamento dos pacientes em hemodiálise. Dois temas principais emergiram das descobertas: os impactos da hospitalização no bem-estar mental, a satisfação do paciente com o cuidado recebido no hospital e a importância de um cuidado coordenado. As experiências pessoais indicaram que a hemodiálise era vista como um rim artificial e um filtro — algo de importância crítica, porém trabalhoso e desafiador em sua necessidade, além de impactar a qualidade de vida. Os desafios enfrentados pelos pacientes incluíam questões de bem-estar mental, como depressão e ansiedade, e limitações financeiras. Para lidar com essas dificuldades, os pacientes recorriam a diversas estratégias, incluindo seguir as orientações dos terapeutas, manter um estilo de vida saudável com exercícios físicos e buscar informações sobre a doença. Também se destacou a grande necessidade de força mental, aceitação e apoio de familiares e amigos, bem como a realização de fisioterapia para resgatar a sensação de normalidade e bem-estar. De modo geral, essa compreensão aprofundada apontará caminhos para melhorias nos sistemas de cuidado e suporte oferecidos aos pacientes.

Palavras-chave
Desafios, enfrentamento, saúde mental

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Introduction

The experience of undergoing hemodialysis for Chronic Kidney Disease (CKD) significantly impacts patients' lives, necessitating substantial lifestyle changes and adjustments for both the individuals and their families. This life-sustaining treatment presents numerous challenges that demand attention and robust support systems. Therefore, understanding the lived experiences of hemodialysis patients, particularly their challenges and coping mechanisms, is paramount. This knowledge can inform the development of targeted interventions to improve their overall well-being and quality of life (Roxo & Barata, 2015). Furthermore, given the increasing global prevalence of CKD and the substantial number of individuals relying on hemodialysis (Sesso et al., 2016; Smeltzer, 2018), research in this area holds considerable practical and societal value.

Despite the existing body of literature on the challenges faced by hemodialysis patients, including strict adherence to treatment regimens, symptom and pill burden, socioeconomic difficulties, and the impact of the COVID-19 pandemic (Hemmett & McIntyre, 2017; Iqbal et al., 2021; Janosevic et al., 2019), several research gaps persist. While depression is widely acknowledged as a prevalent mental health issue in this population (Khalil et al., 2017; Watnik et al., 2018), a more holistic examination of other psychological dimensions, such as anxiety, stress, and cognitive impairment, within diverse patient populations is warranted. Moreover, the interplay between disorganized thought processes and disruptive behaviors requires further investigation (Tohme et al., 2017). Additionally, the literature indicates that the early detection of mental health problems in hemodialysis patients is challenging due to overlapping symptoms with physical ailments (Fountoulakis et al., 2022), highlighting the need for studies that delve deeper into the nuanced presentation of these issues.

Furthermore, while coping strategies employed by hemodialysis patients have been explored (Addison, 2007; Avvenuti et al., 2016; Ghaffari et al., 2019), there is a need for more in-depth qualitative investigations into the specific coping mechanisms utilized by patients facing mental health challenges within the context of their hemodialysis treatment. Understanding these strategies' effectiveness and potential drawbacks is crucial for healthcare providers in developing tailored support and interventions. Moreover, the existing research has been predominantly conducted in Western settings, with a relative scarcity of studies focusing on the experiences of hemodialysis patients in regions like Saudi Arabia (Alhazmi et al., 2019; Dlas et al., 2015; Hou et al., 2018; Ozcan et al., 2015; Sesso et al., 2016).

This study aims to address these research gaps by providing an in-depth exploration of the lived experiences of hemodialysis patients, with a specific focus on their challenges and coping mechanisms. By employing a qualitative approach, this research seeks to uncover the nuances of their experiences beyond the commonly studied aspects of depression, including

anxiety, stress, and potential cognitive issues. Furthermore, this study will specifically investigate the coping strategies employed by patients who are experiencing mental health challenges as they navigate their hemodialysis treatment.

Ultimately, this research contributes to a more comprehensive understanding of hemodialysis patients' challenges and coping mechanisms. By focusing on a specific cultural context, such as Saudi Arabia, this study will provide valuable insights that can inform the development of culturally sensitive and relevant interventions to enhance the quality of life and mental well-being of individuals undergoing hemodialysis. The findings of this study are expected to have significant implications for healthcare professionals, policymakers, and support organizations in their efforts to provide holistic and effective care for this vulnerable population.

Research Method

This study employed a phenomenological approach to determine hemodialysis patients' lived experiences. Phenomenology is research that seeks to explain the nature of things through how people experience them. It translates literally as the "study of phenomena." In other words, it is the study of the meaning these things (or phenomena) have in the participants' minds. Moreover, phenomenological research is a qualitative research approach that builds on the assumption that the universal essence of anything ultimately depends on how its audience experiences it.

Participants

Twenty hemodialysis patients served as participants in this study utilizing purposive sampling. The selection of participants was based on the following criteria: 1) patient at Al Rass Hospital, 2) undergoing hemodialysis in Al Rass Hospital for 3-5 years, and 3) 35 years old and above. After rendering consent, said participants underwent scheduled face-to-face interviews.

This study was conducted at a time when no formal institutional ethics board was established at the Ifugao State University. Consequently, this study did not undergo a formal review by an institutional ethics committee. Nonetheless, prior to data collection, the research protocol was carefully scrutinized for ethical soundness by the Dean of Advanced Studies, the Dean of Health Sciences, and a senior professor with expertise in qualitative methodology at the university. All participants were informed of the study's aims, procedures, and voluntary nature of their participation, including the right to withdraw at any time without penalty. Written informed consent was obtained from all participants. Pseudonyms were used in all transcripts and reports to ensure confidentiality, and audio files and transcripts were securely stored on password-protected devices accessible only to the research team members. The study was conducted in accordance with the ethical standards of Ifugao State University, the Philippine Health Research Ethics Board (PHREB) guidelines, and the principles of the

Declaration of Helsinki, while explicitly acknowledging the limitation that no formal ethics committee approval was possible at the time because of the absence of an ethical review board.

Data Analysis

Since the data collection started, the importance of being open-minded, acknowledging, and accepting what the participants had declared was considered without questioning their interpretations. It was also important that the researchers maintained a good flow of interviews while conforming to the guide questions enumerated in the interview protocol.

Thematic analysis was conducted using Cresswell's (2018) basic interpretative design for this study. The first step required was to transcribe the audio from the recorded interviews, which were repeatedly reviewed to compare and match what was said and what was transcribed. The second step was to scrutinize all the data transcribed to get a general understanding of the information and have the chance to consider its overall significance. The next step is to code the data. In this instance, the transcripts are classified before giving each category a descriptive name. The fourth step uses coding to identify this study's themes and subthemes. This action is crucial because it aids in creating comprehensive descriptions of the results needed in the given statements about the problem. Lastly, the data was interpreted to fully discern the clinical challenges encountered by the participants in patient care. Data saturation was met with the 20th participant. To enhance rigor and trustworthiness, prolonged engagement, member checking, detailed descriptions, and audit trails were observed.

Results and Discussions

Experiences of Hemodialysis Patients

Theme 1. Experiences with Healthcare Providers

Hospitals, doctors, nursing staff, clinics, nursing homes, medical practitioners, nutritionists, dieticians, and many more are examples of healthcare providers. Patients come to hospitals, clinics, and nursing homes to be diagnosed for any injury or condition. Doctors and other medical personnel guarantee that patients receive appropriate care and diagnosis. Hospitals must keep track of their patient's records, diagnoses, medical bills, and other facts (Sapra & Dhaliwal, 2021). In the context of hemodialysis patients' experiences, understanding the role of healthcare providers is critical. Because hemodialysis is a delicate operation, patient care and control during dialysis are critical (Shahgholian & Yousefi, 2018). Exploring how patients view their contacts with healthcare providers provides valuable information.

1.1: *Hospitalization Experiences in Patients' Mental Well-being.*

Being sick and hospitalized is not an easy, regular occurrence and may even be terrifying or traumatic for the patient or his/her family members (Rokach, 2021). Most

participants shared the same experience when they were hospitalized. Hospitalization exacerbates the emotions and increases the depression and anxiety of the participants.

Participant 7 stated,

> *"I feel lonely when I get hospitalized; although my kids or wife are there to tend to me, I do not get to see the outside, and it makes me more anxious, which causes me more stress."*

Participant 14 shared

> *"The ward was crowded with patients, so it was hard for me to sleep."*

Participant 8 added,

> *"It was a hassle since my husband has no place to sleep, and I cannot be left alone."*

Some participants expressed their dismay with the hospital's setup, wherein it is already taking a toll on their mental well-being. These scenarios left an imprint and caused stress for the participants. Hospitalization is a stressful situation that most people will experience at some point in their lives. Many psychosocial consequences can result from the experience, such as uncertainty about the future, anxiety, and depression (Alzahrani, 2021)

1.2: Patient Satisfaction in Hospital.

Patient satisfaction measures how satisfied a patient is with the health treatment they receive from their physician. Patient happiness is one of the most essential variables in determining a healthcare facility's performance. Patients' opinions are regarded as having a critical role in treatment decisions and providing health care services. As a result, the evaluation of health service delivery from patients' perspective has received increased attention. It has become a core element of any health system, serving as a valuable indicator to quantify the success of a service supply, particularly in public sector hospitals (Manzoor et al., 2019). The participants visited their hospitals or healthcare facilities twice or thrice weekly and were satisfied with their services.

Participant 16 stated:

> *"I am satisfied with the Doctor'sDoctor's communication. I understand it easier, and the hospital staff is also nice."*

Participant 10 shared

> *"My Doctor reminds me of the do's and don'ts and the self-care at home since I am divorced, and my kids just visit me from time to time."*

Participant 4 expressed

> *"I visit my Doctor regularly for follow-up consultations."*

Participant 1 added

> *"We usually talk about my treatment and general health."*

Most participants were satisfied with the knowledge provided to them about self-care. Meanwhile, in terms of communication with their doctors and providing necessary information about their current health status, all participants stated that their doctors are detailed in explaining, which is easy for them to comprehend. They also said they meet regularly with their Doctor to discuss their treatment and health. Satisfaction is subjective well-being in different aspects of life, including mental health and the behavior of people experiencing serious health concerns (Iqbal et al., 2021). Patients' satisfaction is relevant in assessing healthcare services (Ahoui et al., 2019).

1.3: Coordination of Care.

Effective communication between healthcare providers is crucial for ensuring the best possible care for patients, particularly those with complex medical conditions like end-stage renal disease (ESRD) who require dialysis. The participants narrated how collaborative and coordinated their doctors are, which is necessary in their treatment process.

Participant 16 expressed:

> *"My doctors are professional and coordinated. They listen to my concerns and give promising options and feedback."*

Participant 2 added,

> *"During hospital visits, I move from one ward to another, and the process is much easier thanks to how my doctors communicate and coordinate their efforts."*

Participant 4 stated:

> *"It would be much more convenient for us if we could also track our detailed medical history from time to time online. It is much of a hassle to ask that from the hospital. Also, it is easier for us to coordinate with our Doctors if we have urgent questions."*

The participants' favorable comments regarding their healthcare providers' team-based approach and the possibilities for online transactions highlight the necessity of excellent communication and collaboration within the healthcare system. Primary care doctors, specialists, and nurses must work together to ensure patients receive comprehensive treatment. Furthermore, the ease of use of online transactions corresponds to the growing relevance of harnessing technology to improve patient-provider relations and streamline healthcare operations. Participants emphasized the importance of providing patient-centered care for patients with chronic renal failure receiving hemodialysis to inspire confidence, develop emotional and social well-being, and maintain treatment adherence. Recognizing and embracing these patients' viewpoints can help inform the development of specialized treatment programs that address the unique requirements of this vulnerable population (Shahgholian & Yousefi, 2018).

Theme 2. Personal Experiences

The participants were asked about their thoughts and feelings about hemodialysis. They were knowledgeable and shared their definition of their treatment. It tries to comprehend how patients perceive and interpret their hemodialysis experience. The topic is divided into numerous themes and subthemes that provide information about various aspects of patients' perspectives.

2.1: Hemodialysis as an Artificial Kidney.

Hemodialysis is one method of treating advanced kidney failure and can allow patients to live an active life despite their failing kidneys. When the kidneys are no longer healthy enough to filter waste, salts, and liquids from the blood, hemodialysis is used. During treatments, patients sit or recline in a chair as their blood passes through the dialyzer, which works as an artificial kidney to clear their blood (Hemodialysis - Mayo Clinic, 2023). Most participants mentioned that hemodialysis is an artificial kidney, as it is an alternative to a kidney, and this is the central theme. There were also sub-themes discovered in the study, namely: (1) hemodialysis as a last option for survival and (2) hemodialysis as an artificial filter to eliminate waste. This theme gives healthcare workers, researchers, and policymakers important information about how they understand treatment.

2.2. Last option for survival.

The participants stated their understanding of hemodialysis. Their attending physician reportedly spoke to them briefly about this. The participants described hemodialysis as an alternative kidney wherein it takes over a portion of the function of the failing kidneys to remove fluid and waste. After this, though, they mentioned that they knew that their illness had gotten worse once they were suggested to undergo hemodialysis. Participant 1 even mentioned,

> *"I know that hemodialysis will be prescribed by my Doctor when my case has worsened, and I did not know that time would come. Still, I'm thankful because I get to live a little longer..."*

Adults in their late 20s might expect to live for up to 20 years or longer on dialysis, whereas adults over 75 may only live for 2 to 3 years. However, dialysis patients' survival rates have improved over the last decade and are likely to continue improving (NHS Choices, 2023). Despite high survival rates, due to their situation, some participants perceive their treatment as their last option for survival. Perceiving dialysis as a last option for survival is understandable, especially for older participants. The participants know it is the last option their doctors can offer once they undergo hemodialysis. According to their understanding, they are at the stage of severe kidney failure, where they can no longer function well.

2.3. Hemodialysis is an artificial filter to eliminate waste.

While most of the participants first mentioned hemodialysis as the last resort of treatment for kidney failure, some participants directly described it. Nine participants stated

that hemodialysis is a treatment to filter waste and water from the blood, as their kidneys did when they were healthy. It helps control blood pressure and balance important minerals, such as potassium, sodium, and calcium, in the blood (*Hemodialysis, 2023).*

Participant 3 shared:

> *"My doctor said that hemodialysis will help my body filter my blood."*

Similarly, Participant 5 said:

> *"Isn't it like a filter of some sort?"*

Participant 12 added:

> *"Hemodialysis does what my kidney is supposed to do."*

The participants all share a standard but oversimplified medical view of hemodialysis as an "artificial filter" that takes the place of normal kidney function. Their statements reflect a common understanding of the treatment's objective: to filter and cleanse the blood necessary to eliminate waste and excess fluid. This phrase simplifies a complex medical process, makes it easier for patients to understand, fits with medical aims, and may provide psychological reassurance. The similarity in their descriptions suggests that participants have a shared understanding, which can improve their involvement with hemodialysis and their general well-being.

2.4: Mixed Feelings about Hemodialysis.

When asked about their feelings regarding hemodialysis, the participants showed mixed reactions. Some expressed shock and fear, while others resigned because they expected it. These reflect the arduous emotional journey many patients go through when presented with this treatment. People with renal failure receiving hemodialysis typically have bad stories, but some keep a positive outlook on life (Gebrie et al., 2023).

Most participants' initial reaction to the news was fear and shock. It was expected that having to undergo hemodialysis meant that their condition was worsening.

Participant 9 said,

> *"When I first heard that there was no other way for me but to undergo hemodialysis, I felt scared not just for myself but for my family as well. I still want to live longer, you know."*

This participant even mentioned being scared for their family as well. Knowing that one's condition worsens evokes fear for the patient and their loved ones. Moreover, younger participants experienced more fear and shock at their worsening condition since they still had their whole lives ahead of them.

Participant 15 mentioned:

> *"Of course, I was scared and shocked. With my age, I am still young, and for me to undergo such treatment had threatened me of death."*

Participant 11 shared:

> *"Honestly, I did not feel anything since I was already expecting it. I can feel it in my system, you know."*

People often feel a whirlwind of emotions when they realize they must begin dialysis. The first reaction is either astonishment or denial. People may also become numb or refuse to realize the situation's truth (Living, 2019). Because this treatment causes significant disruption in one's everyday life, it is normal for people, especially younger ones, to feel shock. Undergoing something you do not fully understand, other than the fact that it will be hard, is expected to cause fear. While most participants were shocked and afraid, some were resigned, as they had already expected this to happen. Since it is their body, they have the foresight to know that their condition is worsening. They had gradually come to terms with the concept. This results in them feeling null about the news of having to undergo dialysis since they already expected it.

Challenges of Hemodialysis Patients

Theme 1: Mental well-being of Hemodialysis patients

It is common to feel unhappy when adjusting to the changes brought on by dialysis. However, for some, the sadness remains. According to studies, nearly one in every five patients with kidney disease suffers from depression. Anxiety is also frequent for those suffering from chronic illnesses (Living, 2019). While these may be true, a few participants had stronger personalities and faced them head-on.

1.1 Depression and anxiety.

Depression is a mental health problem that affects how you feel, think, and act. It can cause you to lose interest in previously appreciated hobbies. Depression symptoms vary from person to person and may overlap with the adverse effects of kidney disease and its treatment. On the other hand, anxiety is a physical reaction to stress. It causes great fear and stress for no apparent reason (Lee, 2022). Many of the participants expressed symptoms of depression. Some notable symptoms shared include a weight shift, feeling like a burden, loss of energy, and reduced physical movement.

Participant 20 shared:

> *"My mental state was bad during the first few months of the treatment. I gained weight and was lying in bed most of the time feeling useless."*

Participant 18 mentioned:

> *"It caused me anxiety because I was really scared. I did not know what would happen to me."*

Participant 15 expressed:

> *"Honestly, it is stressful. This changed a lot in my life. I have to watch what to eat all the time, and I have to go to dialysis biweekly. Not to*

mention all the expenses. It's just stressful."

Being stressed and frustrated in adversity is quite a common reaction. Positive mental well-being is hard enough for the average person to achieve; add undergoing dialysis to that, and you have a bunch of causes for stress. Some participants mentioned being stressed about the financial burden of hemodialysis, while others were frustrated about themselves and their situation. One participant mentioned being stressed about all the changes from undergoing hemodialysis. Notably, eating restrictions are one of the mentioned stressors. The burden of taking multiple medications, deciding what to eat, or being on dialysis can be overwhelming for some. Some individuals can assist if patients are concerned about their emotional state or stress levels. The doctors and mental health professionals at the dialysis clinic are trained to discuss these concerns with patients and help them manage them (Living, 2019)

Theme 2: Financial Constraints

The participants often face challenges and issues that significantly impact their quality of life. A significant percentage of the burden is related to the expenditures associated with managing clinical complexity, comorbidities, lost productivity, and associated premature mortality. Patients undergoing hemodialysis must manage the direct costs of medical treatments, diagnostics, laboratory testing, drugs, immunizations, visits to healthcare providers, hospitalizations, dialysis, transportation to and from appointments, and absenteeism from work due to these issues (Covvey et al., 2017).

Participant 2 shared:

"With my medical bill piling up, I hope there will be more affordable healthcare services."

Participant 17 mentioned:

"Sometimes the queue of follow-up consultations is too long; it's something I want to improve."

Dialysis can be expensive, and financial assistance programs and affordable insurance options can help alleviate the financial burden on patients and their families. Moreover, the participants also mentioned the need for improvement in the process of appointments and outpatient services offered by their healthcare providers. The healthcare system in Saudi Arabia has undergone significant improvements over the years, with the government's significant investments in healthcare infrastructure resulting in increased access to healthcare services across the country. However, despite progress, the system still faces numerous challenges that must be addressed (Gurajala, 2023).

Hemodialysis Patients' Strategies To Cope-Up With Their Mental Struggles and Experiences

Coping is a mechanism for mitigating the impact of various life stressors on

physiological reactions (Addison, 2007). Coping strategies employed by individuals in dealing with chronic diseases could help explain differences in their disease survival rates and their ability to adjust to the challenges experienced while living with the diseases (Reynolds, 2000). This part introduced challenges and coping styles that hemodialysis patients used to respond to unhealthy mental and emotional well-being.

Developing new, healthy behaviors takes time. If one makes a mistake, they should not punish themselves or give up. Instead of lingering on what went wrong, the user should consider how they may handle the issue better in the future and then move on. Chronic kidney disease is a serious condition, but it can be treated. They can take control of their emotional and physical health with the correct tools and support to live a whole and meaningful life (Living, 2019). The participants shared recommendations and advice with fellow individuals undergoing hemodialysis. They also share what to avoid to stay healthy and avoid treatment altogether.

Theme 1: Follow Medical Advice.

When asked what they would recommend to other hemodialysis patients regarding their well-being, most answered that they should do what their Doctor tells them. Some also suggested considering therapy if the strain on your mental health is terrible. Following the Doctor's opinion, it is advised to live a healthy life both physically and mentally.

Participant 6 recommended:

> *"You have to be lenient in following your Doctor because it also helps not just in the course of your treatment but also in your well-being."*

Participant 1 added,

> *"You have to do what your Doctor says and maintain a healthy lifestyle, like strictly following the eating restrictions because it helps you improve your symptoms."*

A healthy lifestyle helps improve your physical, mental, and emotional health. (Managing Your Health, 2015). Thus, you must stick to a dialysis diet (Eight Coping Tips for Dialysis Patients, 2020). Following the advice of a medical practitioner can help you improve as quickly as possible. Doctors complete years of rigorous education and training before practicing medicine and treating patients. They are trained to treat injuries and combat diseases, so medical advice should only be sought from a qualified practitioner (Accel Admin, 2020).

Theme 2: Having a Healthy Lifestyle.

In its most basic form, a healthy lifestyle is a way of life that decreases your chances of becoming very ill or shortens your life expectancy. Although we cannot prevent all diseases, we can prevent many serious illnesses by adopting certain behaviors and avoiding others (Knight, 2021). When asked what could have been done to help the participants avoid being hospitalized, they mentioned being more lenient with how they lived and prioritizing their

health over their past lifestyle.

Participant 20 stated,

> *"I should have avoided taking too many painkillers and energy drinks. I should have drank a lot of water."*

The reference to eating a healthy diet, getting sufficient nourishment, decreasing excess weight, and engaging in regular exercise emphasizes the importance of lifestyle choices in health management (*How to Delay the Onset of Dialysis*, 2023). These elements are, in reality, under the patient's control and can substantially impact their general well-being, particularly in the context of hemodialysis. Individuals undergoing hemodialysis must maintain a balanced diet and manage their nutrition, as dietary restrictions and rigorous monitoring of nutrient intake are frequently part of the treatment regimen. Furthermore, weight control and regular physical exercise play key roles in overall health, slowing the onset of kidney disease and lowering the burden of hemodialysis.

Theme 3: Be educated and take care of yourself.

Each dialysis patient's experience is unique, and gathering information and asking questions can help understand the dialysis treatment and the lifestyle changes accompanying it (*Living Well on Dialysis*, 2019). The standard message from the participants is to take care of and prioritize a healthy lifestyle to avoid the same fate as theirs by being educated and knowing the importance of a healthy lifestyle. Being an active advocate for your healthcare is important. Participants highlighted watching over their diet as it plays a crucial role in CKD since they typically need to watch their sodium, potassium, phosphorus, and fluid intake.

Participant 12 stated:

> *"Collaborative decision is important because my life is not just my own now since getting married."*

Participant 19 also highlighted the importance of second opinions.

> *"Always have second opinions before you decide to go under dialysis."*

Participant 5 mentioned:

> *"Open communication with healthcare providers, treatment adherence, and a proactive approach to managing your health is key to living well as a dialysis patient."*

The participants' emphasis on getting second opinions corresponds to the financial component of undergoing hemodialysis, which can be a considerable financial hardship due to treatment costs. Patients can explore multiple treatment options and access accessible financial help programs by getting second opinions. The results emphasize the importance of patients being well-informed about every aspect of their treatment. Meanwhile, for those with chronic kidney disease, the participants mentioned that they should have collaborative choices

in discussions about long-term planning, including potential kidney transplantation or having hemodialysis and peritoneal dialysis. It should be part of the healthcare conversation.

Theme 4: Mental Fortitude.

Having a strong mental fortitude can be a lifesaver if you have diseases. The ability to be strong in the face of misfortune is called mental fortitude. To get back up and fight after being knocked down. When you are suffering, tired, or bored, it is important to keep your eye on the prize and keep moving forward to show up even when you do not feel like it (Hayden, 2022). Some of the participants showed mental fortitude. Participant 19 responded with,

> *"Maybe it is because I am the eldest in the family. I have always been a fighter since I was already expecting hemodialysis. I faced it bravely and held onto my family for strength and determination to move forward."*

Participant 4 mentioned,

> *"When you have been sick as long as I have, you learn to just face it like the adult we are."*

Participant 19 mentioned being the eldest child. The eldest children are usually hardened mentally since they are the family's breadwinners and must look out for their younger siblings. Thus, it highlights the importance of personal resilience and familial support in coping with the challenges posed by hemodialysis. As stated earlier, some participants accepted their fate long ago, so they remain strong. This outlook emphasizes the need for resilience and adaptability as individuals become accustomed to navigating the complexities of their condition. It also underscores the notion that accepting their medical situation is a fundamental step in managing the challenges of hemodialysis. In a sense, they are battle-hardened, and that battle is undergoing hemodialysis.

Theme 5: Moving Forward

Coping usually involves individuals adjusting to or tolerating adverse events or realities while they strive to maintain their positive self-image and emotional equilibrium. Coping occurs in the context of life changes that individuals perceive to be stressful (Clinic, 2020). For hemodialysis patients, undergoing treatment and everything that comes with it are their stressors. Individuals differ in particular coping styles or prefer specific coping strategies over others. The differences in coping styles usually reflect personality differences.

5.1 Acceptance.

Acceptance was highlighted as a coping method by patients suffering from depression, anxiety, and stress. Most participants cope with undergoing hemodialysis by accepting everything surrounding the treatment. Since they need to undergo treatment, the participants feel they have no choice but to accept it despite the challenges they feel.

Participant 9 even mentioned,

> *"I have no choice but to accept my situation. Although it was difficult for me, my family was there to guide me and support me all the way."*

Most participants mentioned receiving support from their family or friends; this helped them accept the situation despite its challenges. However, some suffered more.

Participant 15 shared,

> *"It was extremely difficult to the point that I was told by my Doctor to seek professional help to cope, so I now undergo talk therapy because I refused to take medications."*

It can be difficult to cope with the stress and difficulties that come with having kidney disease. However, just as one should take care of their physical health, one should also care for their mental health. There is no shame in seeking help. Moreover, the participant mentioned refusing to take medication. There are numerous safe and effective medicines one can take when suffering from issues with mental health. Despite this, it is understandable to be doubtful about taking additional medicines, especially when you already have a kidney disease.

5.2 Strong Support System.

Earlier responses repeatedly mentioned that most participants received support from their families and friends. Support has increasingly been recognized as a crucial aspect that has a favorable impact on the lives of hemodialysis patients and the disease outcome (Theodoritsi et al., 2016). This impact can be seen in the participants as well. They expressed being thankful for having strong support systems during their battle against their disease. This is evident in Participant 16's response.

> *"I'm grateful because I don't feel alone in this battle of life and death."*

It helped the participants have a small positive outlook on life. Participant 9 shared,

> *"Whatever it takes, I always have my family behind my back."*

Knowing they have people they can rely on for support helped them face the hurdles. With this support, they can continue fighting for their right to live in this world. They should be open with others about what they are experiencing and how they are feeling, and they should not be afraid to ask for help. Being on dialysis can be full of ups and downs, so you will benefit from having people to talk to and lean on (8 Coping Tips for Dialysis Patients, 2020; Living, 2019). These responses suggest that this support helps to alleviate the feelings of isolation and despair that can often accompany the difficulties of hemodialysis.

Furthermore, it implies that these interactions provide a source of drive and strength, promoting a more positive view. This constant support strengthens the patient's emotional resilience and provides motivation to endure. This bond and assurance can lead to a greater sense of determination, which is especially important while dealing with a chronic condition.

5.3 Emotional and Social Support.

Chronic diseases have a significant impact on healthcare systems around the globe. In addition to causing pain, complications, and decreased productivity, they affect the patient's family and the whole community (Bakarman et al., 2015). Participants described emotional and social support as the most helpful way to cope. Moreover, none of the participants mentioned anything which was not helpful to them. The emotional support of family members made the patients feel secure and less worried; thus, they considered empathy a concept of care. The most commonly mentioned word by the participants was empathy; casual conversations with their family members made them feel a sense of belonging and showed that they were still functional individuals.

Participant 2 narrated,

> *"My family is my everything, and I can feel their empathy through their actions. I have been in dialysis for over six years now, and I am grateful because my family is there for me every step of the way."*

Participant 6 shared:

> *"The government helps financially through financial aid. My family is my emotional support, and they help me with everything."*

Participant 10 expressed:

> *"People don't understand us, many people pity us but I don't like it."*

Participant 1 also shared

> *"Our neighbors would also comfort me; it helps deal with my frustrations in my health and with our expenses. I feel that I am not alone battling with my illness."*

Participant 12 added

> *"Sometimes, the hospital offers us meals, so that is helpful. For everything else, it's my family that helps me. From finances, medicine, companion and recreation, they're always there, especially my wife."*

Health rights are essential human rights, stated explicitly in Saudi Arabia's Basic Laws in Articles 27 and 31. Furthermore 2006, the Ministry of Health issued a Patient's Bill of Rights (PBR), emphasizing the significance of healthcare accessibility and quality (Al-Amoudi, 2017). This legal basis lays the groundwork for delivering healthcare services, guaranteeing that patients, particularly those undergoing hemodialysis, have the right to proper treatment and assistance.

One participant underscores the importance of emotional support from family members, stating that it is the most important source of assistance. Hence, it emphasizes the critical role of families in providing the support required for those experiencing the hardships

of hemodialysis. Empathy and active support from the family are critical to the patient's well-being. Support is increasingly being recognized as a significant aspect that might improve the lives and outcomes of hemodialysis patients (Theodoritsi et al., 2016). Individuals who have accepted social support from their communities and neighbors share this acknowledgment. Conversations and exchanges with neighbors and fellow residents have become sources of comfort and solace for them, assisting them in navigating the obstacles of their health problems.

However, it is significant to note that a participant expressed a strong resistance to sympathy from others. The participant's preference for aid and support over pity highlights their need for a sense of autonomy and dignity in dealing with their health issues.

A participant also expressed gratitude for the government's financial aid and the hospital's effort during their medical journey. This highlights the significance of government assistance mechanisms, which help to ease the financial constraints that frequently accompany chronic medical treatments such as hemodialysis. The government's participation in giving financial assistance demonstrates its dedication to the well-being of its citizens and communities. The hospital's dedication to providing quality patient care is also notable.

5.4 Maintain activities typically done.

Hemodialysis is a long-term treatment that can be time-consuming. However, there are ways for dialysis patients to cope, adjust to their new normal, and resume their normal day-to-day activities. Going on dialysis does not necessarily mean you cannot work or do other activities. Some patients continue to work full-time while others switch to part-time or flexible schedules (Eight Activities to Try during Dialysis, 2022). Most participants mentioned that they could still do the same routines and chores they did before their dialysis treatment.

Participant 13 mentioned,

> *"I still do the same activities like cooking, cleaning, and tending to my child."*

Participant 17 even stated,

> *"You have to do what your Doctor says and maintain a healthy lifestyle as much as possible. I want to do things on my own and live a normal life; that's why I don't ask for help, but my family is also always guiding me even though I tell them that I can manage."*

The participants' recognition of various limitations on their everyday activities due to hemodialysis highlights the practical obstacles they encounter. While several participants claimed their capacity to conduct simple activities, they also mentioned their inability to move big objects. This constraint is due to the need to protect their vascular access, a surgically constructed vein used in hemodialysis procedures (Department of Surgery - Vascular Access for Hemodialysis, 2014). The fact that participants knew about these limitations and could

handle their activities without asking for help shows how flexible they are and how well they have incorporated the necessary changes into their daily lives. It underlines their determination to manage their health while minimizing disturbances to their daily lives despite certain limitations.

5.5 Physical Therapy.

Renal rehabilitation aims to alleviate symptoms, maintain and promote physical fitness and health, reduce mental burdens, and improve the quality of life of hemodialysis patients. This is implemented through physical therapy (Yusuke et al., 2017). However, none of the participants have been undergoing physical therapy. As mentioned under the above theme, most respondents have been living their lives the same way before they underwent hemodialysis, enjoying activities and hobbies.

Conclusions

Hemodialysis, often perceived as a final option for failing kidneys, elicits a spectrum of emotional responses in patients, including fear, shock, resignation, and anticipation. Alongside these initial reactions, individuals undergoing this treatment frequently grapple with significant mental health challenges like despair, anxiety, stress, and frustration. Despite these difficulties, some patients demonstrate remarkable resilience, often attributed to their past experiences and strong familial support networks, underscoring the vital role of emotional and social support in navigating their condition.

Financial burdens associated with the high treatment costs represent a significant concern for many, highlighting the urgent need for more affordable healthcare options and enhanced financial assistance programs. Furthermore, inefficiencies within the healthcare system, such as lengthy appointment wait times, present additional obstacles that necessitate a more patient-centered approach.

Acceptance emerges as a prevalent coping mechanism, significantly facilitated by the unwavering support of family and friends, although adherence to medication regimens can pose a challenge for some. Promoting a healthy lifestyle through medical guidance and proactive healthcare engagement is crucial to enhancing well-being and emphasizing education and collaborative decision-making in treatment. Ultimately, improving holistic care for hemodialysis patients necessitates providing affordable healthcare, streamlining healthcare systems, offering robust emotional and social support, fostering healthy lifestyle choices, and prioritizing patient-centered care through enhanced coordination and shared decision-making.

Recommendations

To improve the lives of hemodialysis patients, healthcare authorities should prioritize affordable services and financial aid, while healthcare systems should enhance patient

experience and adopt a more patient-centered approach. Establishing programs that offer robust emotional and social support alongside stress management activities is crucial, leveraging the invaluable support of family, friends, and organized networks. Furthermore, healthcare providers must emphasize patient education and actively involve individuals in their care decisions, empowering them with knowledge and promoting healthy lifestyles through proper nutrition, exercise, and adherence to medical advice to bolster their overall well-being.

Disclosure of Conflict of Interest

The authors declare no competing interests.

Ethical Statement

For the ethical considerations of the study, all sources were well cited in the reference list to avoid plagiarism. The participation of the respondents was voluntary and wholeheartedly approved. There was no deception or misinformation regarding the true purpose of the research towards the respondents. The respondents were also encouraged to discuss their concerns regarding the study. In addition, the respondents had the right to withdraw their participation from the research at any time if they wished to do so, and most importantly, the respondents were not subjected to any harm or danger throughout their participation or withdrawal. Personal information was strictly treated with confidentiality. The terms used in formulating the interview guide were ensured to be appropriate, understandable, and sensitive for the respondents; thus, the researchers avoided vulgar, offensive, absent, or other unacceptable language.

Conflict of interest statement: The authors declare that they have no financial, commercial, personal, or academic relationships that could be perceived as influencing the results or interpretation of this manuscript.

Artificial intelligence use declaration: Generative artificial intelligence tools were used solely for linguistic editing, reference standardization, and improvement of textual clarity. The tools were not employed to generate ideas, hypotheses, interpretations, analyses, results, or scientific conclusions. The authors confirm that the manuscript contains no fabricated, manipulated, or fully AI-generated content, and that all information has been manually verified. The authors assume full ethical and scientific responsibility for the final content.

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Data availability

The data underlying the research are reported in the article

Responsible editors

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