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Living with Hemodialysis Due to Chronic Kidney Disease: A Phenomenological Study of Quality of Life

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ABSTRACT

Patients with chronic kidney disease undergoing hemodialysis experience significant changes in quality of life, including physical, psychological, spiritual, and social aspects. The therapy leads to physical limitations, loss of autonomy, and reduced self-efficacy, which may impair patients' ability to manage their condition and increase the risk of stress, depression, and complications. This study aimed to explore patients' experiences and identify self-efficacy-related factors affecting quality of life among hemodialysis patients at Prof. Dr. W. Z. Johanes Kupang Hospital. A qualitative phenomenological approach was employed using in-depth interviews with 10 informants. Data were collected using unstructured interview guides, supported by audio recordings and field notes, and analyzed using the Stevick-Colaizzi-Keen method. Findings indicated that, physically, most patients reported bodily lightness, improved sleep quality, and increased ease in daily activities following routine hemodialysis; however, some continued to experience dizziness, pain, and unstable physical conditions. These physical changes were associated with patients' self-efficacy, where improved conditions increased confidence in managing daily activities and treatment, while persistent symptoms reduced confidence in controlling their health condition. Psychologically, patients initially experienced anxiety, which decreased with adaptation and acceptance. Spiritually, patients showed increased religious devotion as a coping mechanism, while socially, patients maintained interactions with family and their environment, contributing to sustained support. These findings indicate that physical condition, psychological adaptation, spiritual coping, and social support are key factors influencing patients' self-efficacy. Although hemodialysis necessitates complex changes in quality of life, the integration of emotional, spiritual, and social support helps patients in the process of acceptance and adaptation.

Key Messages:

- Hemodialysis causes multidimensional changes in patients' quality of life, affecting physical, psychological, spiritual, and social aspects.
- Reduced self-efficacy and initial psychological distress improve through adaptation, acceptance, and effective coping strategies.
- Emotional, spiritual, and social support are essential in enhancing patients' quality of life during long-term hemodialysis treatment

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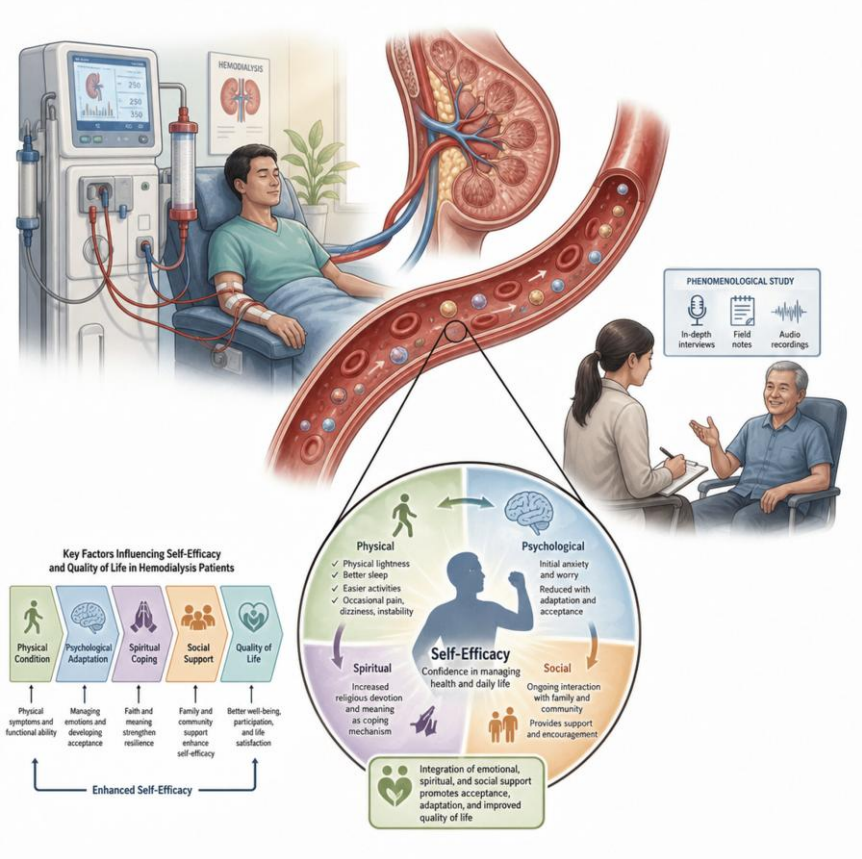
GRAPHICAL ABSTRACT



INTRODUCTION

Chronic Kidney Disease (CKD) is a major global health issue. According to data from the Institute for Health Metrics and Evaluation (IHME), CKD resulted in 1.23 million deaths in 2017. The global prevalence of CKD is 13.4%. The trend of increasing CKD cases undergoing hemodialysis in Indonesia also continues to occur. Data from the Indonesia Renal Registry (IRR) in 2018 shows that the number of new cases is 66,433 people, the number of active patients has increased significantly to 132,142 people. These data indicate the high need for hemodialysis services in Indonesia (1).

The 2023 Survei Kesehatan Indonesia (SKI) shows that Indonesia is a country with a high prevalence of CKD East Nusa Tenggara Province ranks 14th with a prevalence of 11,853 people. In line with this data, Prof. Dr. W. Z. Johannes Kupang Hospital reported that in 2024 there will be 120 CKD patients undergoing hemodialysis, with a total of 139 visits to the hemodialysis room in January 2024. This shows that CKD is a real and significant health problem at the local level.

Hemodialysis therapy is very closely related to the quality of life of patients due to the many complex problems that occur such as physical, psychological, social, economic and spiritual conditions that are the result of hemodialysis and diseases. The condition of a CKD patient for a lifetime dependent on a dialysis machine will result in a gradual change in his or her life (2). The physical impact is weak conditions and the fulfillment of physiological needs such as physical, eating, resting, breathing, and impaired circulation. Spiritually, the patient reveals an increase in getting closer to God, since experiencing illness and undergoing therapy. Economically, patients are facilitated by government health insurance, but patients also incur transportation costs, meals during therapy, and drug costs which make financial needs increase, this is exacerbated by the condition of not being able to work due to weakened physical condition.

The management of CKD is also influenced by psychological factors, one of which is self-efficacy. Self-efficacy is an individual's belief in his ability to achieve a certain level of performance that affects the way a person thinks, feels, motivates himself, and behaves in dealing with his health condition (3). Self-efficacy plays a role in determining the amount of effort expended, the length of resilience in facing obstacles, and the level of individual resilience in dealing with adverse situations (4).

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Bandura explained that self-efficacy has three dimensions, namely magnitude, generality, and strength. These three dimensions help individuals in making choices of action and building a commitment to maintain the behavior that has been chosen. In the context of CKD patients, self-efficacy is an important factor in supporting adherence to self-care regimens, including diet management, medication, and hemodialysis schedules (4). However, many CKD patients have difficulty controlling their disease in their daily lives. This condition is often accompanied by decreased confidence in the ability to deal with various limitations due to chronic kidney disease. Low self-efficacy can affect the patient's decision-making in undergoing treatment, thus impacting the overall success of disease management (5).

Patients undergoing hemodialysis does play an important role in maintaining survival, but on the other hand it also brings significant changes to the patient's lifestyle pattern (6). These changes include dietary arrangements, sleep and rest patterns, medication consumption, daily activities, as well as the emergence of emotional problems such as stress due to illness, medication side effects, physical limitations, and dependence on hemodialysis therapy. These changes have the potential to have a significant impact on the quality of life of CKD patients (4).

Quality of life is a state in which a person gets satisfaction or enjoyment in daily life (7). The quality of life concerns physical health and mental health which means that if a person is physically and mentally healthy then that person will achieve a satisfaction in his life. The quality of life in patients with chronic kidney disease will experience a poor quality of life, due to the lack of willingness to live quality of life who has begun to resign themselves to the state of their disease (8). Therefore, this study aims to explore the experiences of patients with chronic kidney disease undergoing hemodialysis and to identify self-efficacy-related factors that affect their quality of life.

METHODS

The research method used is qualitative research to explore and understand the meaning considered by a number of individuals or groups (9) This qualitative research uses a phenomenological approach, which is to describe a certain phenomenon based on the life experiences experienced by the participants. This phenomenological approach emphasizes on a person's subjective experience (9) Where the phenomenological approach describes the experience that is felt, and consciously known by a person (10) The qualitative phenomenological method in this study is used because it is in accordance with the phenomenon to be revealed, namely the quality of life of patients with chronic kidney disease who undergo hemodialysis therapy.

The informants in this study were patients with chronic kidney disease who underwent hemodialysis. The informant retrieval technique in this study uses purposive sampling, which is based on samples taken by deliberate selection that are adjusted to the research objectives based on the characteristics of the desired subject (11) This study involved 10 informants. The criteria in this study use inclusion criteria and exclusion criteria. The criteria that must be met by participants in order to become informants in this study:

1. Patients diagnosed with chronic kidney disease (CKD) by medical personnel.
2. Adult patients (age ≥18 years) and able to provide information consciously.
3. Have undergone hemodialysis routinely for more than 1 year.
4. Able to communicate and listen well.
5. Be willing to participate in the study by signing an informed consent sheet.
6. Not having an acute condition (e.g. severe infection, active bleeding that may affect the quality of the interview).

Criteria rendering a patient ineligible include:

1. Patients with cognitive or mental impairments that may interfere with the interview process (e.g. dementia, psychotic disorders)
2. Patients with hearing loss or speech assistance without alternative communication

In-depth interview is a data collection method that aims to obtain in-depth and detailed information from sources. This method is used to explore research topics that are complex and require more in-depth exploration to understand the experiences, views, and meanings conveyed by informants.

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The questions asked in the in-depth interview were related to the three dimensions of self-efficacy, namely magnitute, generality, strength and four dimensions of quality of life, namely physical health, psychological health, social relationships, and spiritual environment.

In data collection, an instrument was used, namely interview guidelines and a triangulation of sources. Data were collected through direct interviews conducted in the waiting room of the hemodialysis unit at Prof. Dr. W. Z. Johanes Kupang Hospital. The study was carried out in June 2025. Data analysis was carried out using the Stevick-Colaizzi-Keen model consisting of stages 1). Grouping units in the meaning of the theme; 2). Making synthesis (textural description); 3). Maintaining the reflection of the structural explanation of oneself through the variation of the imagination, the researcher makes a structural description construct; 4). Explain each meaning and essence of the phenomenon.

CODE OF HEALTH ETHICS

This research has received ethical approval from the Research Ethics Commission of the Faculty of Public Health, Nusa Cendana University (No.000102/KEPK FKM UNDANA/2025). After obtaining ethical approval, the researchers, assisted by the head nurse of the hemodialysis unit, approached patients who met the criteria. The researcher explained the research procedure and asked for informed consent from the respondents.

RESULTS

The key informant in this study is CKD patients with Hemodialysis at Prof. Dr. W.Z. Johannes Kupang-NTT Hospital. The characteristics of the informants are further illustrated in table 1.

Table 1. Key Informant Characteristics

No	Participant Code	Age	Gender	Education Level	Occupation	Duration of Hemodialysis
1	Informant A	68	Female	Junior High School	-	3 years
2	Informant B	62	Female	Senior High School	Housewife	13 years
3	Informant C	62	Female	Senior High School	Housewife	5 years
4	Informant D	69	Female	Primary School	Housewife	2 years
5	Informant E	69	Male	Diploma	Retired	2 years
6	Informant F	49	Male	Senior High School	Self-employed	5 years
7	Informant G	61	Male	Bachelor's Degree	Retired	4 years
8	Informant H	61	Male	Senior High School	Self-employed	3 years
9	Informant I	51	Female	Bachelor's Degree	Housewife	4 years
10	Informant J	61	Male	Bachelor's Degree	Self-employed	4 years

Physical Condition

Based on the results of the interviews, it is known that 7 patients stated that their physical condition improved after undergoing regular hemodialysis, the expression can be seen from the following interview excerpts:

"... I feel better and my body feels lighter after hemodialysis" (B)

"I feel lighter... sleep better" (F)

While 3 patients experienced complaints after undergoing routine hemodialysis after undergoing routine hemodialysis, the expression can be seen from the following interview excerpts:

"I feel fresh after hemodialysis... but when I get home... I feel dizzy and need to rest" (D)

Based on the results of the interviews that have been presented, it can be concluded that hemodialysis helps improve physical condition, but the side effects of this hemodialysis still appear in individuals.

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Fatigue After Hemodialysis

Based on the results of the interviews, it is known that 6 patients stated that they were easily tired after undergoing regular hemodialysis, the expression can be seen from the following interview excerpts:

"I usually feel tired... when I do more activities" (H)

While 1 patient stated that fatigue decreased after undergoing hemodialysis, this expression can be seen from the following interview excerpts:

"I used to feel tired easily... but now it has improved." (D)

3 patients stated that they did not feel tired after undergoing hemodialysis, the expression can be seen from the following interview excerpts:

"I do not feel tired..." (C)

Limitations in Daily Activities After Hemodialysis

Based on the results of the interviews, it is known that 7 patients stated that they did not have difficulty in carrying out daily activities when they had undergone hemodialysis regularly, the expression can be seen from the following quote:

"I have no difficulty... because I can manage my time." (C)

While 3 patients stated that they had difficulties in their activities and limited their daily activities, the expression can be seen from the following interview excerpts:

"I cannot do anything now... I cannot even wash clothes... and I cannot cook if I have to stand for a long time." (A)

Based on the results of the interviews that have been presented, it can be concluded that the physical activity of patients is limited due to their physical condition, but the routines they do every day can make them independent.

Psychological Response

Anxiety During Hemodialysis

Based on the results of the interview, it is known that 7 patients stated that they had been anxious at the beginning of undergoing hemodialysis, but as time went by they became accustomed to undergoing treatment, this expression can be seen from the following interview excerpt:

"...at first... I felt anxious, but after a long time undergoing hemodialysis, I got used to it..." (B)

"I felt anxious at the beginning... but now I am used to it." (F)

While 3 patients stated that they did not feel anxious, the expression can be seen from the following interview excerpt:

"At first... I thought hemodialysis would only last one or two months... now I feel fine and there is no anxiety anymore." (A)

Based on the results of the interviews that have been presented, it can be concluded that the anxiety experienced by the patient is temporary, over time they are able to adapt to undergoing treatment.

Hopelessness and Acceptance After Hemodialysis

Based on the results of the interviews, it is known that 6 patients stated that they were desperate when they found out they had to undergo hemodialysis, but as time went by, the patient was able to accept the situation, this expression can be seen from the following interview excerpt:

"Since the beginning... I have already accepted it... I must accept my condition." (E)

"At first it was difficult... but gradually I accepted the situation." (G)

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While 4 patients stated that they received a fairly positive reception if they knew they would undergo hemodialysis, the expression can be seen from the following interview excerpt:

"I am not hopeless… I just prepare myself mentally and go through it with gratitude." (H)

Based on the results of the interviews that have been presented, it can be concluded that the patient's self-acceptance is the final stage of the patient's emotional adaptation process to the condition being undergone.

Stress-Coping Activities Among Patients

Based on the results of the interviews, 6 patients stated that they cope with stress with activities such as watching, household activities, going for a walk or fishing, the expression can be seen from the following interview excerpts:

"When I feel stressed… I go out for a walk or go fishing." (F)

"I usually watch something… like videos on my phone or Facebook." (G)

While 4 patients stated that they cope with stress by praying, the phrase can be seen from the following interview excerpt:

"When I feel stressed… I pray to calm myself." (A)

Based on the results of the interviews that have been presented, it can be concluded that light activities and spiritual activities can help patients to overcome stress and maintain psychological balance during hemodialysis.

Spiritual Responses

Spiritual Relationship With God After Hemodialysis

Based on the results of the interview, it is known that 7 patients stated that there was no significant change because the relationship with God was still the same, the expression can be seen from the following interview excerpt:

"I feel my relationship with God is still the same… I still attend morning reflection." (A)

"Nothing has changed… in fact, illness makes us closer to God." (C)

While 3 patients stated that they were getting closer to God after undergoing regular hemodialysis, the phrase can be seen from the following interview excerpts:

"My relationship with God is getting closer… I become closer to Him through illness." (D)

Based on the results of the interviews that have been presented, it can be concluded that spirituality increases and becomes a source of strength and calm for patients. Based on the results of the interview, it is known that 7 patients said that the moment of prayer before and after undergoing treatment made them feel closer to God, this expression can be seen from the following interview excerpt:

"I always pray before and after hemodialysis… it makes me feel closer to God." (I)

"Prayer makes me feel closer to God and more peaceful." (F)

While 3 patients stated that pain and anxiety were moments of reflection in undergoing treatment, the expression can be seen from the following interview excerpts:

"When I feel anxious… I always pray a novena and feel closer to Mother Mary." (A)

Based on the results of the interviews that have been presented, it can be concluded that spiritual moments occur naturally, especially when the patient is facing treatment.

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The Presence of God in the Treament Process

Based on the results of the interviews, it is known that 10 patients said they felt God's presence while undergoing treatment, the phrase can be seen from the following interview expressions:

"I know I am not alone… God is with me." (I)

"I feel God's presence during hemodialysis… He is always beside me." (H)

Based on the results of the interviews that have been presented, it can be concluded that spiritual beliefs are the main factor for patients to survive physically and emotionally.

Social Interaction

Patients' Relationships With Their Families After Hemodialysis

Based on the results of the interview, it is known that 10 patients stated that they had a good and supportive family, the expression can be seen from the following interview excerpt:

"My children always support me and are always there for me." (A)

"My family always supports me and stays close to me." (C)

Based on the results of the interviews that have been presented, it can be concluded that family support is the strength and encouragement of the patient's successful adaptation during hemodialysis.

Feelings of Closeness or Social Withdrawal After Hemodialysis

Based on the results of the interview, it is known that 9 patients stated that they were closer to their families and environment, the expression can be seen from the following interview expressions:

"I feel closer to my family and neighbors… I prefer to stay connected with people." (A)

"I feel closer to my loved ones after becoming sick." (E)

While 1 interview stated that initially he had withdrawn but has now re-adapted to the social environment, the expression can be seen from the following interview excerpt:

"I used to withdraw when I was very weak… but now I am back to normal social interaction." (H)

Based on the results of the interviews, it can be concluded that hemodialysis can strengthen social bonds.

Frequency of Patients' Interactions With Family, Neighbors, and the Surrounding Community

Based on the results of the interview, it is known that 10 patients stated that they were still actively interacting well with the people around them, the expression can be seen from the following interview excerpt:

"I still talk with neighbors and attend social activities like usual." (A)

"I still interact with friends and community groups." (B)

Based on the results of the interviews that have been presented, it can be concluded that social interaction plays an important role in patients to maintain emotional stability.

Meaningful Support for Patients During Hemodialysis

Based on the results of the interview, it is known that 7 patients expressed support from their families, the quote can be seen from the following interview expressions:

"My family always supports me and takes care of me." (E)

"My wife and children always understand and stay with me." (G)

While 2 patients expressed support from the Rouhani environment, the expression can be seen from the following interview excerpt:

"The church community always prays for me, and I feel relieved." (B)

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And 1 patient expressed support from the patient and the patient's family:

"People around me support each other and strengthen one another." (I)

Based on the results of the interviews that have been presented, it can be concluded that emotional, spiritual, and social support is very meaningful support during hemodialysis.

DISCUSSION

Physical condition

Hemodialysis successfully reduces physiological fluids or toxins, the body still adapts to changes in internal conditions. This is in line with Al-Naamani et.al (12) shows that the physical fatigue experienced by hemodialysis patients affects quality of life and overall physiological changes. Fatigue is a fairly common complaint found at the beginning of hemodialysis therapy. Activities carried out by patients, both light and heavy, can trigger fatigue, but in this condition they improve over time. This shows that there is an adaptation that the patient experiences significant fatigue towards regulated activities so that the patient's condition remains stable. This is in line with the research of Alshammari et.al (13) showing that there are factors that affect fatigue in hemodialysis patients which include age, length of time to undergo hemodialysis and other physical changes. Fatigue management not only addresses symptoms, but involves activities, education, and clinical support that optimize the patient himself. Patients are able to adjust activities according to their physical condition. Research by Van Westrum et.al (14) shows that the patient's fatigue and physical limitations affect daily activities and require safe activity support for the patient. The environment is essential for patients to be able to move safely and comfortably. This adaptation reflects the magnitude dimension of self-efficacy, as patients gradually expand their perceived capability from limited physical activity to managing daily routines within their physical limits. Research by Pratiwi et al. further indicates that self-efficacy is related to patients' ability to manage daily activities and self-care behavior during hemodialysis, particularly in adapting to physical limitations during treatment(15).

Psychological response

The results of the study found that there are two phases, the first is the despair/rejection phase and the second is the acceptance phase. Over time, the patient is able to adapt and accept with gratitude. Patient acceptance, family support can speed up the admission process and reduce the psychological burden on patients. Patients experience anxiety when they are first diagnosed to undergo therapy. The rate of acceptance of the disease is the main factor that affects the psychological well-being of patients. But as time goes by and gets used to it, the anxiety felt by the patient decreases. This is in line with the research of Junjun Wen *et.*al (16) showed that there are important factors for disease acceptance and coping style in patients undergoing hemodialysis. In addition, research from Sahaf et al. (17) suggests that the anxiety felt by patients at the beginning of treatment is an interpretation that interventions that include education, psychological preparation of the patient and social support can help reduce anxiety and turn into acceptance. Patients who are stressed due to the hemodialysis process do many ways to overcome stress ranging from praying, light household activities, and entertainment. Research from Sagala and Pasaribu (18) shows that healthy coping style is proven to improve the quality of life of hemodialysis patients. These psychological adjustments reflect the strength dimension of self-efficacy, where patients' confidence in controlling emotional distress increases over time, and the generality dimension, as coping strategies such as prayer, relaxation, and activities are applied across different stressful situations.

Spiritual attitude

Patients maintain and improve religious routines after undergoing treatment. This shows that the experience of undergoing therapy makes the patient spiritually strong. This is in line with Santos *et.*al (19) shows involvement in active religious activities in patients with chronic diseases, for example spirituality as a patient coping during treatment. The sick condition encourages the patient to increase existential reflection and strengthen spiritually. This is a process of adaptation from treatment procedures to spiritual meaning. Spirituality can provide a sense of security and provide inner comfort to the patient. This is in

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line with Santos *et.*al (19) shows that coping from the spiritual has a positive impact and improves the quality of life. This reflects the strength dimension of self-efficacy, as spiritual belief enhances patients' confidence in facing illness, and the generality dimension, as spirituality is consistently used as a coping resource across different stages of treatment.

Research by Rahmah et al. which reports that religious-based interventions such as listening to spiritual recitations are associated with improved emotional calmness and reduced stress among hemodialysis patients (20).

Social Interaction

The family is the main support system in the process of adapting patients to their conditions. This is in line with Dewi *et.*AL (21) shows that family support plays an important role in the approach to compliance and quality of life because patients feel accepted and cared for. Positive social support and interaction were associated with a decrease in depressive symptoms and an increase in the morale of hemodialysis patients (22). Patients use social media to maintain communication with distant families, in addition to social media, patients also participate in community activities such as social gatherings, environmental prayers and church activities. The most meaningful support comes from the nuclear family, spiritual support, and support from fellow patients and patients' families (23). Patients feel emotional and spiritual power from the presence of those closest to them, which helps them to go through the treatment process more patiently. This represents the generality dimension of self-efficacy, as patients transfer confidence gained from social support into broader daily functioning, while also reinforcing strength, as continuous support increases persistence in long-term treatment adaptation.

This is further supported by a study in a local hospital setting which found that strong family support is closely associated with better quality of life and improved adaptation among patients undergoing hemodialysis, as emotional and practical assistance from family members helps patients cope more effectively with long-term treatment (24).

CONCLUSION

This phenomenological study provides an understanding of the quality of life of patients with chronic kidney disease undergoing long-term hemodialysis. Hemodialysis affects physical, psychological, spiritual, and social aspects of patients' lives. Physically, patients reported improved comfort and daily functioning, although fatigue remained common. Psychologically, initial anxiety and distress gradually improved through adaptation and coping strategies. Spiritually, hemodialysis strengthened patients' closeness to God and provided inner peace. Socially, family support and social interaction played an important role in adaptation and emotional stability. Overall, self-efficacy across its three dimensions (magnitude, generality, and strength), together with acceptance and multidimensional support, were key factors in improving patients' quality of life. These findings emphasize the need for a holistic, patient-centered approach in hemodialysis care.

DECLARATION OF THE USE OF AI

The authors declare that no artificial intelligence (AI), AI-assisted technologies, or large language models (LLMs) were used in the conception of the study, data analysis, or the drafting, writing, and editing of this manuscript. The only exception is the graphical abstract, which was created using the design platform Illustrae (https://illustrae.co/). The authors take full responsibility for the content and accuracy of the graphical abstract and the entire manuscript.

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CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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