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Lived Experiences of Young Adults Aged 22−29 Years with Chronic Kidney Disease Undergoing Hemodialysis: A Qualitative Study

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ABSTRACT

Background: Chronic kidney disease (CKD) is a major global health concern, affecting around 850 million people and contributing significantly to morbidity and mortality. It is increasingly diagnosed in young adults, yet their experiences with long-term hemodialysis remain underexplored, particularly in nursing care. ***Purpose*:** This study aims to explore the lived experiences of young adults with CKD undergoing long-term hemodialysis. ***Methods*:** A qualitative study with a phenomenological approach was conducted in the hemodialysis unit of a public hospital in West Java, Indonesia. Five participants aged 22-29 years who had undergone hemodialysis for at least one year were recruited through purposive sampling. Data was collected through semi-structured, in-depth interviews and analyzed using Interpretative Phenomenological Analysis. ***Results*:** Five themes emerged: (1) Lifestyle Patterns and Delayed Recognition of Illness; (2) Emotional Responses and Disrupted Sense of Self; (3) Disrupted Social Relationships and Support Systems; (4) Physical Burden and Activity Limitation; and (5) Coping, Spirituality, and Hope for the Future. Hemodialysis was perceived as a life-altering event that affected independence, education, employment, and relationships. Participants described shock, fear, stress, and social withdrawal, especially in the early phase of treatment. Over time, family support, nurse engagement, peer interaction, and spiritual practices fostered acceptance, resilience, and sustained hope. ***Conclusion*:** Hemodialysis represents a profound multidimensional transition for young adults with CKD. Despite significant challenges, participants demonstrated adaptive coping and personal growth. ***Implications for Nursing:*** Holistic, age-sensitive nursing care that integrates emotional support, family involvement, spiritual sensitivity, and individualized coping interventions is essential to enhance quality of life and long-term adaptation.

Keywords: Chronic kidney disease, Hemodialysis, Lived experiences, Qualitative study, Young adults.

What does this paper add?

1. This study highlights how young adults experience hemodialysis as a major life disruption during a critical developmental stage, affecting their education, employment, relationships, and sense of independence.
2. The findings reveal the central role of family support, peer interaction, spirituality, and nurse-patient relationships in helping young adult patients adapt, sustain hope, and rebuild meaning in life.

3. This paper provides context-specific insights from Indonesian young adults, offering practical guidance for nurses to design more holistic and age-sensitive care for young adult patients undergoing long-term hemodialysis.

Introduction

Chronic kidney disease (CKD) is a progressive and irreversible condition that leads to the deterioration of renal function and affects multiple organ systems. In its advanced stage, often referred to as end-stage renal disease (ESRD), young adult patients require renal replacement therapy, such as hemodialysis or kidney transplantation, to sustain life (Susan C. Smeltzer, 2016). Globally, CKD has emerged as a major public health concern, contributing to more than 850,000 deaths annually and affecting approximately 850 million people worldwide, making it one of the leading non-communicable causes of morbidity and mortality (Global Burden of Disease, 2020; World Health Organization, 2023).

In recent years, a notable epidemiological shift has occurred, with CKD increasingly affecting individuals at a younger age. While CKD was traditionally associated with older adults and degenerative comorbidities, current data indicates a rising prevalence among adolescents and young adults, particularly those aged 13-29 years (Indriani et al., 2022; Kementerian Kesehatan, 2023). This issue is particularly concerning, as young adulthood represents a critical developmental period characterized by educational attainment, career establishment, social integration, and long-term life planning. The diagnosis of CKD and the need for lifelong hemodialysis during this phase can significantly disrupt these developmental trajectories.

Hemodialysis, although life-sustaining, imposes substantial physical and psychosocial burdens on young adult patients. The rigid treatment schedule, dietary restrictions, physical fatigue, and dependence on medical technology often limit daily activities and social participation (Kalantar-Zadeh et al., 2021). For young adults, these limitations may result in emotional distress, uncertainty about the future, social withdrawal, and challenges in maintaining employment or educational pursuits (Pratiwi et al., 2022). Previous studies have shown that young adult patients undergoing hemodialysis frequently experience reduced quality of life, heightened psychological stress, and impaired social functioning (Kerklaan et al., 2020).

Beyond physical consequences, CKD and long-term hemodialysis exert profound psychological, social, and spiritual impacts. Young adult patients often face stigma, altered self-identity, and financial strain related to ongoing treatment costs and loss of productivity (Indriani et al., 2022; Pius Berek et al., 2025). At the same time, family support, healthcare professional engagement, and spiritual beliefs have been identified as important resources that help young adult patients cope with the demands of chronic illness and sustain hope (Appiah et al., 2022; Fitri Mailani et al., 2024). Spirituality and religiosity, in particular, have been reported to play a significant role in fostering acceptance, resilience, and meaning-making among young adult patients undergoing long-term hemodialysis.

Despite the growing number of young adults affected by CKD, research exploring their lived experiences remains limited, especially within the context of nursing care. Most existing studies focus on clinical outcomes or older patient populations, leaving a gap in understanding the unique challenges faced by younger individuals who are navigating chronic illness alongside critical developmental tasks. A deeper exploration of their experiences is essential to inform holistic, age-sensitive nursing interventions that address not only physical needs, but also psychosocial and spiritual dimensions of care.

Therefore, this study aims to explore the lived experiences of young adults with chronic kidney disease undergoing hemodialysis, using a phenomenological approach. Understanding these experiences is expected to provide valuable insights for nursing practice and contribute to the development of more comprehensive and empathetic care strategies tailored to the needs of young adults living with CKD.

Background

Chronic kidney disease (CKD) is a progressive and irreversible condition that requires lifelong management and, in advanced stages, renal replacement therapy, such as hemodialysis (Kalantar-Zadeh et al., 2021). Globally, CKD contributes substantially to morbidity and mortality, affecting millions of people and placing a significant burden on health systems (Global Burden of Disease, 2020). Although traditionally associated with older adults, recent evidence indicates a growing

number of adolescents and young adults living with CKD, raising concerns about its impact during a critical developmental period (Ramadhan et al., 2026).

For young adults, the need for long-term hemodialysis may interfere with education, employment, social relationships, and future life plans. Previous studies have shown that young adult patients undergoing hemodialysis frequently experience psychological distress, reduced social participation, and altered life perspectives (Rao et al., 2025; Woei Ling et al., 2024). Understanding how young adults interpret and live through this condition is essential to inform holistic and age-sensitive nursing care.

Methods

Study Design

This study used a qualitative phenomenological design to explore the lived experiences of young adults with chronic kidney disease undergoing hemodialysis. The phenomenological approach enabled an in-depth understanding of participants' subjective perceptions and meanings related to living with long-term hemodialysis across physical, psychological, social, and spiritual dimensions.

The checklist used in this study followed the EQUATOR guidelines, specifically the Consolidated Criteria for Reporting Qualitative Research (COREQ), which consists of 32 items.

Setting

This study was conducted at the hemodialysis unit of dr. Soekardjo Regional Public Hospital, Tasikmalaya City, West Java, Indonesia. The hospital is a public healthcare facility that provides regular hemodialysis services for young adult patients with chronic kidney disease. Data collection was carried out between August and September 2025 in a clinical setting that allowed participants to share their experiences in a comfortable and private environment while undergoing routine hemodialysis treatment.

Interviews were conducted during hemodialysis sessions with careful consideration to minimize participant burden. Participants were interviewed during stable phases of treatment, and the interviews were paused or adjusted if participants experienced discomfort, fatigue, or clinical procedures. This approach was chosen to ensure convenience and reduce additional hospital visits, while maintaining participants' comfort and safety throughout the data collection process.

Study Participants

Participants were young adults diagnosed with chronic kidney disease undergoing long-term hemodialysis. Participants were selected using purposive sampling based on predefined inclusion and exclusion criteria. Eligible participants were aged between 22 and 29 years, had been receiving hemodialysis for at least one year, were clinically stable, and were able to communicate in Indonesian or Sundanese.

The age range was intentionally limited to 22-29 years to ensure a relatively homogeneous group within young adulthood and to align with the idiographic focus of Interpretative Phenomenological Analysis (IPA). Participants who were newly diagnosed with chronic kidney disease, had undergone hemodialysis for less than one year, or were receiving peritoneal dialysis were excluded from the study.

A total of five participants were included, and recruitment continued until data saturation was achieved. Data saturation was reached after the fifth participant, as no new codes or themes emerged from subsequent interviews. This was confirmed through iterative analysis, where repeated patterns and meanings were consistently identified across participants, indicating sufficient depth and richness of the data in line with the principles of IPA.

Data Collection and Ethical Consideration and Analysis

Data was collected through semi-structured, in-depth interviews conducted between August and September 2025. Each interview lasted approximately 30-60 minutes and followed an interview guide consisting of open-ended questions designed to explore participants' lived experiences. Probing questions were used to gain deeper insights.

Field notes were taken during and after interviews to capture non-verbal expressions and contextual details.

Data collection and analysis were conducted concurrently, and recruitment ceased once no new themes emerged across interviews, indicating saturation across participants rather than within a single interview.

Ethical approval for this study was obtained from the Ethics Committee of the Faculty of Nursing, Universitas

Islam Sultan Agung Semarang (Approval No. 1260/A.1-KEP-K/FIK-SA/VIII/2025). Before data collection, all participants received a clear explanation regarding the study objectives, procedures, potential risks, and their rights as research participants. Written informed consent was obtained from each participant before participation. Confidentiality and anonymity were strictly maintained by using codes instead of personal identifiers, and all data was stored securely with access limited to the research team. Participants were informed of their right to withdraw from the study at any time without any consequences to their treatment.

This study adopted Interpretative Phenomenological Analysis (IPA), which is grounded in phenomenology, hermeneutics, and idiography. IPA aims to explore how individuals make sense of their lived experiences through a process of double hermeneutics, where participants interpret their experiences and researchers, in turn, interpret those interpretations.

Data was analyzed to gain an in-depth understanding of participants' lived experiences. Audio-recorded interviews were transcribed verbatim, and each transcript was reviewed repeatedly to achieve immersion in the data. Initial notes were made to identify significant statements, emotional expressions, and meaningful patterns. The analysis was conducted idiographically, focusing on detailed examination of each individual case before identifying patterns across participants. Emerging themes were developed and examined within each case, followed by identifying connections across cases.

This iterative and interpretative process allowed for the exploration of both convergence and divergence of meanings while preserving the uniqueness of each participant's experience.

Results

Five young adults with chronic kidney disease participated in this study. Participants shared relatively homogeneous characteristics in terms of educational level, employment status, marital status, and ethnicity. All participants were clinically stable and able to share their experiences clearly during the interviews, providing rich descriptions of living with chronic kidney disease and long-term hemodialysis.

Table 1. Characteristics of participants (n = 5)

No.	Code	Age (Years)	Education Level	Occupation	Marital Status	Ethnicity
Male						
1.	L1	27	Senior High School	Unemployed	Single	Sundanese
2.	L2	22	Senior High School	Unemployed	Single	Sundanese
3.	L3	25	Senior High School	Unemployed	Single	Sundanese
Female						
1.	P1	29	Senior High School	Unemployed	Single	Sundanese
2.	P2	23	Senior High School	Unemployed	Single	Sundanese

Table 1 presents the demographic characteristics of the study participants. A total of five young adults with chronic kidney disease participated in this study, consisting of three males and two females. Participants' ages ranged from 22 to 29 years. All participants had completed senior high school education and were unemployed at the time of data collection. None of the participants was married, and all of them were identified as Sundanese. These characteristics indicate a relatively homogeneous group in terms of educational background, employment status, marital status, and ethnicity, while still representing both male and female perspectives among young adults undergoing long-term hemodialysis.

Emergent Themes

Theme 1: Lifestyle Patterns and Delayed Recognition of Illness

Participants described various lifestyle patterns and health-related behaviors that they believed contributed to the development of chronic kidney disease. Unhealthy eating and drinking habits, irregular daily routines, and limited attention to early health symptoms were commonly reported. Most participants acknowledged that they had not considered kidney health a priority before being diagnosed.

In addition to drinking habits, participants also described irregular daily routines and a tendency to neglect early symptoms, including delaying medical

consultation despite persistent fatigue and swelling.

To explore possible risk factors and lifestyle patterns before the diagnosis of chronic kidney disease, participants were asked:

"Chronic kidney disease usually develops over time due to certain habits or lifestyle patterns. Can you tell me what your daily habits were like before you were diagnosed, and what things you used to do that might have contributed to your condition?"

"Basa eta osok sering minum kemasan anu dingin geuning a jiga ale-ale, teh kotak, teh pucuk, ari minum air putih mah jarang geuning a, jarang sarapan oge a" (L3)

"I used to frequently drink cold packaged beverages, such as flavored drinks and bottled tea. I rarely drank plain water and often skipped breakfast." (L3)

Another participant also mentioned that since childhood, he was not accustomed to drinking plain water, as expressed below:

"Ti aalit abi jarang pisan bahkan henteu pernah minum cai herang a. Pami e'eut cai teh bawaan na teh sok langsung mual we asa sebel a" (L1)

"Since childhood, I rarely, even rarely, drank plain water. Whenever I tried to drink water, I immediately felt nauseous and uncomfortable." (L1)

Furthermore, another participant explained unhealthy dietary habits, as illustrated in the following statement:

"… karena kirang minum air putih, minum teh seringna anu minuman berasa wae nu dingin geuning…" (L2)

"…because I did not drink enough plain water, I mostly drank tea and other flavored beverages, usually cold." (L2)

The early symptoms experienced by participants were often vague and not immediately associated with kidney disease. Common complaints included persistent fatigue, decreased appetite, nausea, leg swelling, and reduced urine output. Because these symptoms were perceived as mild or temporary, many participants delayed seeking medical care. The diagnostic process was described as sudden and overwhelming, particularly when participants were informed that their condition had reached an advanced stage requiring immediate hemodialysis. Receiving the diagnosis at a young age caused emotional shock and confusion.

"Awalna mah lambung a, nyeri ulu hati, teras nyeri teh dugi kana pinggang…" (L2)

"At first, I experienced stomach problems, pain in the upper abdomen, and then the pain spread to my lower back." (L2)

"Awalna mah bengkak a, teras sesak berat napas teh …" (P2)

"At first, I experienced swelling, followed by severe shortness of breath." (P2)

"Teu aya tanda-tanda a, langsung sesak we sareng napas teh asa beurat…" (L1)

"There were no warning signs; I suddenly experienced shortness of breath, and my breathing felt very heavy." (L1)

Another participant stated that he did not experience any symptoms beforehand and suddenly developed severe shortness of breath until losing consciousness at home, as described in the following statement:

"Teu aya tanda - tanda a, langsung sesak we sareng napas teh asa beurat. Di bumi teh abi dugi ka teu sadar pingsan…" (L1)

"There were no warning signs; I suddenly experienced shortness of breath, and my breathing felt very heavy. At home, I eventually lost consciousness and fainted." (L1)

Another participant experienced different complaints, including weakness and easy fatigue, as expressed in the following statement:

"Bengkak, sesak, lelelus, gampang cape a" (L3)

"Swelling, shortness of breath, weakness, and easy fatigue." (L3)

The same participant also reported that during the initial period of undergoing hemodialysis, she was frequently hospitalized due to recurring complaints, such as shortness of breath and swelling.

"Sok sesak, bengkak a. Pokonamah pami tiap aya keluhan langsung we sok di candak ka IGD geuning a" (P2)

"I often experienced shortness of breath and swelling. Whenever any symptoms appeared, I was immediately taken to the emergency department." (P2)

Theme 2: Emotional Responses and Disrupted Sense of Self

Living with long-term hemodialysis had a profound psychological impact on participants. Feelings of stress, frustration, uncertainty about the future, and fear of complications were commonly expressed. Participants described concerns about life expectancy, independence, and long-term goals. To cope with these challenges, participants adopted various strategies that extended beyond psychological responses. These included psychological coping (acceptance and positive thinking), social coping (sharing feelings and spending time with family and friends), and spiritual coping (strengthening faith and surrendering to God).

These findings indicate that coping among participants was multidimensional, involving psychological, social, and spiritual processes rather than purely emotional regulation.

Several participants reported that these psychological conditions gradually diminished after they had undergone hemodialysis for several sessions.

To understand participants' emotional responses and how they perceived themselves after the diagnosis, participants were asked:

"When you first found out that you had chronic kidney disease and needed hemodialysis, how did you feel at that moment, and what thoughts came to your mind about yourself and your future?"

"Stres mah pasti aya wae a, komo pas awal - awal mah. Lebih ke pasrah we geuning a" (L2)

"Stress was definitely there, especially at the beginning. I eventually became more resigned and accepting." (L2)

"Pernah a, pasti aya wae a. Komo pas awal - awal cuci mah" (L3)

"Yes, I experienced it as well. It was definitely there, especially during the early stages." (L3)

In addition to stress, several participants also expressed feelings of hopelessness related to their current condition, as reflected in the following statement:

"Ngaraoskeun a sadayana aya, stress, depresi sareng asa putus asa we ti pas awal terang abi gagal ginjal dugi ka ayeuna ge dugi ka teu tiasa bobo na." (P1)

"I felt everything, stress, depression, and a sense of hopelessness, from the moment I found out that I had kidney failure until now, and it has even affected my ability to sleep." (P1)

"Tahun pertama mah muhun a emosi teh henteu stabil, asa tos putus asa we a. Tapi abi ngemutna sanes ka diri abi, tapi abi ngemutna ka keluarga a" (L1)

"During the first year, my emotions were unstable, and I felt completely hopeless. However, my thoughts were not focused on myself, but rather on my family." (L1)

Participants expressed a wide range of emotional responses following diagnosis and initiation of hemodialysis. Initial reactions commonly included disbelief, fear, sadness, and anxiety. Many participants struggled to accept the reality of having a chronic, lifelong condition at a young age. Feelings of anger, helplessness, and emotional instability were also reported, especially during the early phase of treatment. Over time, emotional responses evolved as participants gradually adapted to their condition, although emotional distress remained present.

"Panik sareng tegang a pasti" (L2)

"I felt panicked and tense, for sure." (L2)

Participants described feelings of shock accompanied by disbelief regarding their condition. Several participants reported that they never expected the mild symptoms that they had experienced to be signs of a serious illness.

"Leleus we a asa teu percaya abi kedah cuci darah" (P2)

"I just felt weak and couldn't believe that I had to undergo hemodialysis." (P2)

Similar feelings were expressed by another participant, who experienced stress and excessive worrying after hearing the doctor's explanation. The participant reported disbelief and difficulty accepting the diagnosis, particularly because of his young age.

"Stres we a, kapikiran nu jauh - jauh geuni a. komo abi kan masih keneh muda a, asa teu percaya we a, henteu menerima" (L3)

"I just felt stressed and kept overthinking everything, especially because I'm still young, I couldn't believe it and had difficulty accepting it." (L3)

Another participant expressed a similar emotional response, including feelings of disappointment, mental confusion, and difficulty accepting the diagnosis delivered by the doctor, as reflected in the following statement:

"Kecewa we a, pikiran teh asa berantakan, henteu menerima oge abi pas dokter ngobrol gagal ginjal teh" (L1)

"I just felt disappointed; my thoughts were all over the place, and I couldn't accept it when the doctor talked about kidney failure." (L1)

Hemodialysis was described as a physically and emotionally demanding experience that significantly altered participants' daily lives. Participants reported physical discomfort during and after treatment, including fatigue, weakness, dizziness, and pain at the vascular access site. The strict treatment schedule, typically several times per week, limited flexibility and personal freedom. Participants also described feelings of dependence on machines and healthcare services, which reinforced a sense of vulnerability and loss of control.

One participant described feeling physically weak and shocked after learning that hemodialysis would need to be carried out for the rest of his life.

"Leleus a, panik sugan teh cuci darah teh cekap ngan sekali atos weh, ari pek teh kedah rutin" (L2)

"I felt weak and panicked. I thought that dialysis would only be needed once, but it turned out that it had to be done regularly." (L2)

In addition, one participant reported feeling fear when undergoing hemodialysis for the first time. This fear emerged, because the participant had never received hospital-based treatment previously.

"Sieun a, jaba jarum na ageung pisan, komo abi mah acan pernah ka RS a. Asa teu percaya we a abi di cuci teh" (L3)

"I was scared, especially since the needle was really big, and I had never been to that hospital before. It felt unbelievable to me that I was being treated there." (L3)

Living with chronic kidney disease led participants to reflect deeply on the meaning of life. Many described changes in personal values and priorities, with greater appreciation for health, family, and everyday experiences. Participants reported becoming more grateful, patient, and reflective. The illness experience encouraged them to redefine life goals and find meaning beyond physical limitations, highlighting personal growth despite ongoing challenges.

All participants expressed that they now value their health and time more.

"Lebih menghargai waktu a, lebih menghargai pisan kana kesehatan oge a" (L1) (L2) (L3) (P2)

"I value my time more and also appreciate my health greatly." *(L1) (L2) (L3) (P2)*

Another participant stated that her illness experience has changed her perspective on life. She realized that if time could be reversed, she would have taken better care of her health from the start.

"Kesehatan itu mahal. Andai pami waktu bisa diulang panginten abi bakal lebih ngajaga kana kesehatan" (P1)

"Health is precious. If time could be reversed, I would take even better care of my health." (P1)

Several participants experienced significant emotional distress, including stress, feelings of hopelessness, and sleep disturbances, particularly during the early phase of hemodialysis.

"Asa putus asa we a, stress di bumi teh hese bobo…" (P1)

"I felt hopeless and stressed, and I had difficulty sleeping at home." (P1)

One participant underwent his first hemodialysis session while unconscious and later described feeling as though it was a dream, along with difficulty accepting the situation after regaining consciousness.

"Abi sadar - sadar teh kan di ruang HD a nuju cuci darah, asa nyimpi we a abi nuju di HD, asa nyimpi di gigireun abi aya mesin HD teh, teu nampi we a" (L1)

"When I regained consciousness, I found myself in the hemodialysis room undergoing dialysis. It felt like a dream, seeing the dialysis machine beside me. I couldn't accept it." (L1)

Theme 3: Disrupted Social Relationships and Support Systems

Chronic kidney disease and hemodialysis affected participants' social lives and interpersonal relationships. Participants reported reduced social interaction due to physical limitations, treatment schedules, and feelings of embarrassment or discomfort. Some participants withdrew from social activities and felt disconnected from their peers of the same age. Difficulties maintaining friendships, romantic relationships, and social roles contributed to feelings of isolation and loneliness.

While participants experienced social disconnection, they simultaneously identified support from family, peers, and healthcare professionals as essential in coping with their condition.

Some participants experienced social distancing from peers after being diagnosed with chronic kidney disease and starting hemodialysis. They noticed friends acting differently, but still assumed good intentions, understanding that their health condition now, such as fatigue, was different from before.

To explore changes in social relationships and sources of support, participants were asked:

"After you were diagnosed and started hemodialysis, what changes did you experience in your relationships with family, friends, or your partner, and who has been the most supportive for you during this time?"

"Ngaraos a. Babaturan asa ngajauh a. …" (P2)

"I feel like my friends are kind of distancing themselves..." (P2)

Some participants reported that their long-term relationships ended after their partners learned about their chronic kidney disease and need for hemodialysis, even in cases where marriage was planned after college.

"Gaduh a, ngan ti pas awal abi kedah HD janten si istri eta teh tos putus janten kabur a" (L2)

"I had a girlfriend, but as soon as I had to start hemodialysis, she broke up and disappeared." (L2)

"… Kabogoh ge janten ngajauhan a hehehe" (L3)

"...My partner also started distancing herself, hehehe." (L3)

"… Kabogoh oge anu asalna pami tos lulus kuliah teh abi rencana na bade nikah, dugi ka ninggalkeun na a" (L1)

"...My partner, with whom I had planned to marry after college, ended up leaving me." (L1)

Support from family members and healthcare professionals was described as a key factor in participants' ability to cope with their illness. Family support included emotional encouragement, assistance with daily activities, financial help, and accompaniment to dialysis sessions. Participants also valued supportive communication from nurses and other healthcare professionals, particularly when they felt listened to, understood, and cared for. This support helped participants feel more motivated and less alone during treatment.

For some participants, family was the main source of support during hemodialysis, providing not only physical help, but also emotional encouragement, helping them accept their condition and stay motivated.

"Keluarga paling a. Pami rerencangan mah sapertos biasa we a" (L2)

"Maybe my family. Friends are just as usual." (L2)

"Ngadukung sagala na a. Osok nganganteur tiap abi HD, dugi bapak henteu full damel deui jiga basa eta a" (P2)

"They support everything, often taking me to every hemodialysis session, to the point my father no longer works full-time like before." (P2)

"Sadayana alhamdulillah ngasih support a, mung orang tua nu ngasih support terbesar ka abi" (P1)

"Everyone, thankfully, gives support, but my parents provide the greatest support to me." (P1)

"Mamah osok nganter - nganter tiap HD" "Muhun a. osok sering nyariosan wae, nga semangatan" (L3)

"My mother often takes me to every hemodialysis session, keeps reminding me, and encourages me." (L3)

"Keluarga paling a anu masih dukungan terbesar mah. Mamah sareung bapak alhamdulillah tiasa nganteur abi tiap abi cuci atanapi tiap abi kontrol a, janten abi oge kamotivasian oge a" (L1)

"My family probably gives me the greatest support; alhamdulillah, my parents can take me to every dialysis session and check-up, which also motivates me." (L1)

Besides family support, young adult patients also receive support from fellow young adult patients and their families. Social interactions during and outside hemodialysis, including WhatsApp groups, allow sharing experiences and strengthen a sense of community, helping them feel less alone.

"Nya kitu we a saling ngobrol, inti na mah saling nguatkuen sesama pasien sareng keluarga teh a" (L2)

"Just chatting, mainly to support each other among young adult patients and their families." (L2)

"Ngobrol - ngobrol biasa we a, osok ngawartosan saha anu maot geuning a, pada saling nga informasikeun we a" (P2)

"Just casual chatting, sharing news about anyone who passed away, simply exchanging information." (P2)

"Saling ngamotivasian sareng saling nguatkeun a, pami aya pasien nu teu hadir teh langsung di chatan atanapi di teleponan" (P1)

"They motivate and support each other; if a patient is absent, they are immediately messaged or called." (P1)

"Nya kitu we a saling ngobrol, saling nga semangatan, pami aya nu maot teh osok ngabaran" (L3)

"Just chatting and encouraging each other, and sharing news if someone passes away." (L3)

Beside support from family and patient communities, healthcare workers, especially nurses, play a crucial role. They provide hemodialysis care, motivation, knowledge, and emotional support, helping young adult patients and families understand the condition while their empathy fosters calmness and encourages treatment adherence.

"Penting pisan a. Sering masihan terang elmu, tina asalna tidak tahu jadi tau geuning a ayeuna mah. Pami misalna teu aya perawat mah mereun abi teu tiasa HD a" (L2)

"Very important. They often share knowledge, turning what I didn't know into understanding. Without nurses, I might not be able to undergo hemodialysis." (L2)

"Pami teu aya perawat maha abi panginten moal tiasa HD a dugi ka ayeuna. Alhamdulillah osok ngamotivasian oge perawat na oge a" (P2)

"Without nurses, I probably wouldn't be able to continue hemodialysis until now. Thankfully, they also motivate me." (P2)

"Penting pisan a. Pami teu aya perawat mah abi panginten moal tiasa dugi ka waktos ayeuna. Perawatna oge alhamdulillah bageur sok masih motivasi, semangat ka pasien - pasienna" (P1)

"Very important. Without nurses, I might not have made it this far. Thankfully, they are kind and motivate young adult patients." (P1)

"Penting pisan a. Pami teu aya perawat mah panginten abi moal tiasa cuci darah a, moal tiasa kieu" (L3)

"Very important. Without nurses, I might not be able to undergo hemodialysis or be like this now." (L3)

"Penting pisan a. Pami teu aya perawat sareng nu sanesna abi moal tiasa jiga kieu a. Pami misalna abi nuju katingal ngeluh perawat oge sok ngobrol nyaketan ngamotivasian abi, nganyemangatan a" (L1)

"Very important. Without nurses and others, I wouldn't be like this. If I seem to be struggling, nurses come over, talk to me, and motivate me." (L1)

Theme 4: Limitations in Daily Activities

Participants experienced significant limitations in daily activities as a result of physical weakness, treatment schedules, and medical restrictions. These limitations affected their ability to work, continue their education, perform household tasks, and engage in leisure activities. Many participants described a loss of independence and reliance on others for daily needs. Adjustments to daily routines were required to accommodate treatment demands and physical condition.

One participant stated that they can no longer

work as usual due to their current physical condition, which makes them easily fatigued.

To identify the physical impact and limitations in daily life, participants were asked: *"Since undergoing hemodialysis, how has your physical condition affected your daily activities,, such as work, study, or other routines?"*

"Ngaruh pisan a. Anu asalna basa eta abi tiasa damel keneh ayeuna mah janten teu tiasa da gampil cape tea sareng bisi aya nanaon pami damel teh. Paling sareng ameng teh ayeuna mah rada dikirangan a henteu sapertos basa eta." (L2)

"It affects me a lot. I used to be able to work, but now I can't, because I get tired easily and worry that something might happen while working. Even leisure activities are now reduced compared to before." (L2)

Some participants reported that regular hemodialysis required adapting to a new routine. Initially, they struggled with scheduling activities and had trouble sleeping, but over time, they adjusted.

"Pami ayeuna mah alhamdulillah tos tiasa menyesuaikan a. Pami basa eta mah muhun a asa rieut we geuning a, dugi ka hese bobo na." (P2)

"Now, alhamdulillah, I can adjust. Before, it was confusing and even caused trouble sleeping." (P2)

Other participants similarly reported that fatigue prevents them from working as usual and forces them to reduce daily physical activities.

"Ngaruh pisan a. Janten teu tiasa damel ayeuna mah, aktivitas ge janten dikirangan da gampang cape a." (L3)

"It affects me a lot. I can't work now, and I've had to reduce activities, because I get tired easily." (L3)

Some participants avoid strenuous daily activities, fearing their physical condition may worsen during tasks like work.

"Tina main janten rada dikirangan a da gampil cape tea, sareng ayeuna mah sieun kangge damel teh da bilih karaos pas nuju di tempat damel." (P1)

"Playtime is reduced, because I get tired easily, and now I'm afraid to work, worrying about how my body will feel at the workplace." (P1)

For participants who were still studying, hemodialysis affected their academics, forcing them to stop college due to reduced physical strength and changes in social activities.

"Berpengaruh pisan a. Anu asalna basa eta abi kuliah ayeuna mah janten atosan, anu biasana abi sering ameung ayeuna mah janten ngirangan a" (L1)

"It affects me a lot. I used to attend college, but now I've stopped, and activities that I used to do often are now reduced." (L1)

Physical fatigue and reduced energy significantly limited participants' daily activities. Many participants reported having to reduce social and recreational activities due to feeling easily tired after undergoing hemodialysis.

"Paling maen janten rada di batasi a, da gampil cape oge geuning a ayeuna mah" (P1)

"Maybe playtime is a bit limited now, because I get tired easily." (P1)

"... Ayeuna mah maen oge dikurangi da eta gampil cape tea a" (P2)

"...Now I also play less, because I get tired easily." (P2)

"... aktivitas rada dikirangan da gampil cape tea a ..." (L1)

"...Activities are slightly reduced, because I get tired easily." (L1)

The financial burden associated with long-term hemodialysis was a major concern for participants. Costs related to treatment, transportation, medications, and nutritional needs created ongoing financial pressure. In addition, participants' inability to work or maintain stable employment led to reduced income. Many participants reported financial dependence on family members, which contributed to feelings of guilt and emotional stress.

One participant reported having to pay extra for hospital transportation and additional medication if the supplied drugs ran out before the next appointment.

"Terkendala, masing tina HD na mah ditanggung ku pemerintah tapi aya biaya anu kaluar a sapertos ongkos bensin gening a da abi berangkat ngangge motor. Sareng paling kedah ngaluarkan acis kangge meser obat a ka apotek" (L2)

"There are challenges. Although hemodialysis is covered by the government, I still have expenses, like fuel for my motorcycle and sometimes need to buy medicine from the pharmacy." (L2)

Another participant similarly stated that, although hemodialysis is covered by the government, additional costs beyond the therapy are still needed.

"Pasti aya wae a, walaupun HD na ti pemerintah oge a" (P2)

"There are always some costs, even though the government covers hemodialysis." (P2)

Another participant reported that tests and transportation costs are significant expenses given their limited finances.

"Eumm, aya a. Ongkos paling a, teras meser obat, cek lab a" (L3)

"Eumm, Yes, there are costs, like transportation, buying medicine, and lab tests." (L3)

Some participants also reported financial challenges from lost income, not just additional expenses, due to being unable to work regularly after starting hemodialysis.

"Pasti a, abi henteu damel otomatis pendapatan teu aya. Sedangkan kan pengeluaran pasti aya sapertos meser obat pami misalna obat anu dipasihan pas kontrol kirang tapi tebih keneh ka kontrol selanjutna, otomatis kedah meser ka apotek" (L1)

"Of course, I don't work, so I have no income. Yet there are expenses, like buying medicine if the supplied drugs run out before the next appointment, which means that I have to buy them at the pharmacy." (L1)

Theme 5: Coping, Spirituality, and Hope for the Future

Spirituality emerged as an important source of strength for participants in coping with chronic illness. Participants described increased reliance on religious beliefs, prayer, and spiritual reflection after being diagnosed with chronic kidney disease. Spiritual practices helped participants find comfort, manage emotional distress, and accept their condition. Many viewed their illness as a test or part of a larger life purpose, which provided emotional relief.

One participant stated that hemodialysis made them more aware of their limitations and the importance of surrendering to God.

To explore coping strategies, spirituality, and future expectations, participants were asked: *"Living with chronic kidney disease and regular hemodialysis can be challenging. How do you usually cope with these challenges, and what keeps you strong and hopeful about your future?"*

"Lebih dekat deui a, karena sieun maot tea. Memang basa eta pas awal - awal mah abi kantos nyalahkan ka allah naha abi hungkul nu kieu teh, tapi abi menerima we a pasrah. Pasrah teh dalam arti abi nuju berjuang a" (L1)

"I feel closer to God because of the fear of death. At first, I even questioned why this happened to me, but I accepted it and surrendered, meaning that I am still fighting." (L1)

Another participant stated that their illness brought them closer to God, improving their prayer and religious practices, which they often neglected before.

"Ngaruh a. Janten asa lebih caket we a. Anu basa eta abi masih bolong - bolong sholat na ayeuna mah alhamdulillah janten getol a" (L3)

"It has an impact. I feel closer to God. I used to miss prayers, but now, thankfully, I am consistent." (L3)

Another participant stated that their closeness to God provides both calmness and strength during hemodialysis.

"Berpengaruh a. Kumaha nya a, abi basa eta jujur osok jarang sholat teh, osok ninggalkeun wae sholat. Ayeuna mah alhamdulillah teu aya anu kalangkung sholat teh a, ngaos alhamdulillah osok a ayeuna mah hehehe" (L2)

"It has an impact. Honestly, I used to rarely pray and often missed it. Now, thankfully, I don't miss prayers and enjoy reading the Quran." (L2)

Another participant similarly reported changes in their religious practices since starting hemodialysis.

"Berpengaruh a, janten lebih dekat sareng Allah, ibadah na oge ayeuna mah janten lebih getol deui a hehehe" (P2)

"It has an impact; I feel closer to Allah, and my religious practices are now more diligent." (P2)

Another participant similarly reported feeling closer to God after undergoing hemodialysis.

"Berpengaruh pisan a. Ti pas awal HD ayeuna mah janten langkung getol ibadahna, lebih caket we sareng Allah" (P1)

"It has a strong impact. Since starting hemodialysis, I've become more diligent in worship and feel closer to Allah." (P1)

Besides spiritual changes, worship provides inner peace. Participants reported that it helps maintain hope, gratitude, and appreciation for their current health and life.

"Sangat - sangat membantu pisan a, pami misalna abi teu ibadah panginten Allah oge moal ngizinan abi dugi ka umur ayeuna a" (L1)

"It helps a lot. If I didn't worship, perhaps Allah wouldn't have allowed me to reach my current age." (L1)

Despite the challenges of living with chronic kidney disease and hemodialysis, participants continued to express hope. Hope was directed toward improved health, better symptom control, kidney transplantation, or a meaningful life despite illness. Family encouragement, spiritual faith, and trust in medical care contributed to sustaining hope. Hope functioned as a motivating force that helped participants endure treatment and maintain emotional resilience.

All participants expressed their hope to recover from their current illness.

"Hoyong sembuh a" *(L1) (L3) (L2) (P2)*
"I just want to get better" (L1) (L3) (L2) (P2)

One participant stated that she has no other hope besides wanting to recover from their current illness.

"Moal macem - macem a, abi mah cekap hoyong sembuh we" *(P1)*
"Nothing else, I just want to get better." (P1)

Most participants showed good coping skills, often preferring to talk or spend time with close ones to relieve stress.

"Osok di ameungkeun a sareng rerencangan lembur meh kabalieurkeun a kahilapkeun" (L2)

"I like to hang out with friends from my village to be entertained and take my mind off things." (L2)

(Ngobrol dengan keluarha mungkin a, curhat, main HP) (L3)

"Talking with family, venting, or playing on my phone." (L3)

(Jalan - jalan mungkin a, main HP, main game, renang) (L1)

"Going out, using my phone, playing games, or swimming." (L1)

Discussion

Participants in this study reported various lifestyle patterns that contributed to the development of chronic kidney disease, including unhealthy dietary habits, infrequent consumption of plain water, and irregular daily routines. Many admitted that they did not prioritize kidney health before diagnosis. These findings align with previous research indicating that poor nutrition, inadequate water intake, and unhealthy lifestyle behaviors increase the risk of CKD (Escudero-Lopez et al., 2024; Rao et al., 2025).

The early symptoms of CKD reported by participants were often vague, including fatigue, decreased appetite, nausea, and swelling. Many delayed seeking medical care due to mild initial symptoms, leading to sudden and overwhelming diagnoses when advanced CKD was identified, sometimes requiring immediate hemodialysis. Similar experiences have been documented in prior studies, highlighting that delayed recognition of early CKD symptoms can contribute to rapid progression and emotional shock (Ashrafi et al., 2025; Lee & Kim, 2022).

Participants expressed shock, fear, sadness, and anxiety following their diagnosis, particularly given their young age. Over time, some adapted to their condition, although stress and emotional instability persisted. These findings are consistent with prior literature showing that young adult CKD patients frequently experience intense psychological distress, particularly during the early stages of treatment (Byrne et al., 2020; Çam & Uzun, 2024).

Hemodialysis was described as physically demanding, emotionally challenging, and disruptive to daily life. These findings suggest that hemodialysis is not merely a medical treatment, but a biographical disruption that reshapes young adults' sense of normality and future orientation. Participants reported fatigue, weakness, dizziness, and pain at the access site. The rigid treatment schedule reinforced feelings of dependency and loss of control. Previous qualitative studies similarly describe hemodialysis as both a physical and psychosocial burden that limits independence and impacts quality of life (Woei Ling et al., 2024; Yip, 2021).

Beyond emotional distress, participants' narratives reflect a deeper disruption of identity, where being a "young adult" is redefined through dependency on medical technology and loss of autonomy. Hemodialysis was not only experienced as treatment, but also as a constraint that reshaped their sense of normality and future orientation.

Participants reported stress, hopelessness, fear, and uncertainty about the future, particularly during the initial stages of treatment. Coping strategies included acceptance, positive thinking, engagement in leisure activities, sharing emotions with family or friends, and reliance on spiritual beliefs. This is consistent with prior findings that young adult CKD patients use a combination of problem-focused and emotion-focused coping strategies to manage psychological distress (Bahtiar et al., 2022; Li et al., 2025).

Chronic kidney disease and hemodialysis altered social interactions. Participants described distancing from peers, disruptions in romantic relationships, and reduced participation in social activities due to fatigue or treatment schedules. These social consequences echo previous research indicating that CKD negatively affects social engagement, contributing to isolation and emotional stress (Derasin, 2025; Ibrahim et al., 2022).

Family support, including emotional, practical, and financial assistance, was crucial in helping participants cope with CKD. Nurses and healthcare professionals were also key sources of motivation, guidance, and emotional support. This aligns with existing literature emphasizing that social and professional support improves patient adherence, emotional well-being, and treatment outcomes (Hilyatun Nisa & Hafifah, 2025; Woei Ling et al., 2024).

Physical weakness and treatment demand limited participants' ability to work, study, perform household tasks, and engage in leisure. Participants often had to adjust routines and reduce activities. Prior studies similarly report that CKD and hemodialysis impose substantial restrictions on daily functioning, reducing independence and quality of life (Almutary et al., 2025; Ge et al., 2025).

Participants faced significant financial challenges, including transportation costs, medications, and other healthcare-related expenses, compounded by reduced income due to the inability to work. These findings are consistent with previous research highlighting the economic burden of CKD and long-term hemodialysis on young adult patients and their families (Pangalila et al., 2020; Ritte et al., 2020).

Spirituality emerged as a central coping mechanism. Participants described increased closeness to God, regular prayer, and reliance on faith as sources of comfort and strength during treatment. These experiences mirror previous studies showing that spiritual practices can buffer psychological distress and improve resilience among young adult CKD patients (Çam & Uzun, 2024; Darvishi et al., 2020).

Despite physical, social, and financial challenges, participants maintained hope for recovery or improved quality of life. Hope was strengthened by family support, spirituality, and trust in healthcare providers. Consistent with prior studies, hope functions as a critical motivator, enhancing resilience and treatment adherence in young adult CKD patients (Bayan et al., 2024; Hreńczuk, 2021).

Living with CKD prompted participants to reflect on the value of health, time, and relationships. Many reported greater gratitude, patience, and personal growth, redefining life goals beyond physical limitations. Previous research confirms that chronic illness can lead to meaningful personal reflection and re-prioritization of values, fostering growth and resilience (Hoang et al., 2022; Sousa et al., 2024).

The findings should be interpreted within the Indonesian sociocultural context, where family involvement, religious beliefs, and collectivist values strongly influence illness experiences and coping processes.

Implications for Nursing

The findings of this study highlight the need for holistic and age-sensitive nursing care for young adults

undergoing long-term hemodialysis. Nurses should not only focus on the physical management of treatment, but also address the psychological, social, and spiritual challenges experienced during this critical stage of life. Emotional distress, uncertainty about the future, and social withdrawal were common among participants, particularly in the early phase of diagnosis and treatment. Therefore, nurses play a key role in providing therapeutic communication, emotional reassurance, and continuous encouragement to support adaptation.

Family involvement should be actively integrated into nursing care, as family support was identified as a primary source of strength for young adult patients. Nurses can facilitate family education, promote open communication, and encourage collaborative care planning. In addition, acknowledging young adult patients' spiritual needs and respecting their beliefs may enhance coping and resilience. Developing individualized care plans that consider developmental stage, life goals, and social roles is essential to improve the quality of life and long-term adjustment among young adults receiving hemodialysis.

Conclusions

This study highlights that hemodialysis represents a profound disruption in young adults' lives, affecting their sense of identity, independence, and future orientation. Despite these challenges, participants demonstrated resilience through multidimensional coping, including social support and spirituality, enabling them to reconstruct meaning and sustain hope.

These findings emphasize the importance of holistic and age-sensitive care to support young adults in navigating the complex challenges of chronic illness.

Limitations

This study has several limitations. The findings were based on participants' self-reports, reflecting subjective interpretations of living with chronic kidney disease and undergoing hemodialysis; therefore, the results cannot be generalized to the broader population. Additionally, the small sample size and relatively homogeneous participant characteristics may limit the diversity of perspectives captured. However, the sample size is consistent with IPA's idiographic approach, which prioritizes depth over breadth to provide a detailed understanding of lived experiences. Although data saturation was achieved, future research should include larger and more diverse samples, as well as longitudinal approaches to better understand how adaptation evolves over time. Furthermore, recall bias may have occurred, as participants reflected on past experiences.

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Conflict of Interests

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Author Contributions

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