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Understanding the dialysis journey: A qualitative study of patients' lived experiences

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Abstract
Background: Chronic kidney disease and its treatment through dialysis represent a profound life transition. While clinical outcomes are well-documented, the subjective, lived experience of patients navigating the dialysis journey is less understood but critical for providing holistic, patient-centered care.
Methods: This qualitative study employed a phenomenological approach. In-depth, semi-structured interviews were conducted with a purposive sample of 25 patients undergoing in-center hemodialysis. Data were analyzed using inductive thematic analysis to identify key themes and patterns.
Results: The analysis revealed four central themes characterizing the dialysis experience: [1] Loss of Autonomy and Identity, where patients grappled with the treatment's all-consuming schedule and its impact on their sense of self; []2 Navigating a New Reality, encompassing the physical toll of treatment and the complex process of dietary and fluid management; [3] The Dialysis Unit as a Dual Space, describing the unit as both a lifeline and a site of anxiety, and a community of shared suffering; and [4] Psychological Turbulence, which included experiences of anxiety, depression, and existential uncertainty about the future.
Conclusion: The dialysis journey is a complex biographical disruption that extends far beyond a medical procedure. It necessitates significant psychological, social, and existential adjustments. A deeper understanding of these lived experiences is essential for healthcare providers to move beyond purely technical care and develop interventions that support patients' holistic well-being, ultimately improving their quality of life.

Keywords: Dialysis, hemodialysis, lived experience, qualitative research, chronic kidney disease, patient-centered care, quality of life, end-stage renal disease (esrd)

Introduction

Chronic Kidney Disease (CKD) is a major global public health concern, with millions of patients worldwide progressing to its end stage (ESRD), a condition necessitating renal replacement therapy for survival [1, 2]. Dialysis, primarily in-center hemodialysis, serves as the most common life-sustaining treatment for ESRD, performing the vital functions of filtering toxins and removing excess fluid that the failed kidneys can no longer manage [2]. The clinical efficacy of dialysis is measured through objective biomarkers such as urea reduction ratio, electrolyte balance, and fluid management, and its success in prolonging life is unequivocal.

However, the experience of living on dialysis transcends these physiological parameters. The initiation of dialysis marks a critical and often traumatic biographical turning point—a "biographical disruption" as described by Bury [4]—where one's sense of self, future plans, and daily routines are fundamentally shattered. The treatment regimen is demanding, typically requiring patients to spend three to four hours per session, three days a week, tethered to a machine within the clinical environment of a dialysis unit. This rigid schedule imposes severe restrictions on employment, social activities, travel, and family life, effectively medicalizing a patient's existence.

While the quantitative literature extensively covers morbidity, mortality, and clinical adherence rates in this population, it often fails to capture the rich, nuanced, and deeply personal subjective reality of the individuals enduring this treatment. Understanding the *lived experience*—the patients' perceptions, emotions, adaptations, and the meanings they assign to their illness and treatment—is paramount. It is this understanding that forms the foundation for truly patient-centered care, which aims to align treatment with patients' own goals, values, and definitions of quality of life [5].

Previous qualitative studies have begun to explore this terrain, highlighting challenges such as loss of independence [6], symptom burden [7], and the impact on mental health [8]. Yet, a comprehensive, contemporary exploration that synthesizes the multifaceted dimensions of the entire dialysis journey—from the practical daily struggles to the profound existential questions it raises—remains crucial. Healthcare providers, often focused on clinical metrics, may lack insight into the silent struggles their patients face outside the dialysis unit.

Therefore, this study aims to address this gap by employing a qualitative phenomenological approach to explore the holistic lived experiences of patients undergoing in-center hemodialysis. Our central research question is: What is the essence of the lived experience for patients navigating the journey of dialysis? We seek to understand the physical, psychological, social, and existential impact of this life-sustaining treatment. The findings intend to give voice to patient narratives, providing clinicians, policymakers, and support services with the deeper contextual understanding needed to develop more empathetic, supportive, and effective care models that address the whole person, not just the failing kidneys.

Methods

StudyDesign

This study employed a qualitative, phenomenological research design. Phenomenology is concerned with the

detailed understanding and description of human lived experiences, aiming to explore the essence of a phenomenon as perceived by those who have experienced it [9]. This approach was deemed most appropriate to richly capture the subjective realities and meanings patients assign to their dialysis journey.

Participant Selection and Recruitment

A purposive sampling strategy was used to recruit participants who could provide rich, information-dense accounts of the phenomenon under study. Recruitment took place over a three-month period at a large, urban dialysis center. Inclusion criteria were: [1] adults aged 18 years or older; [2] diagnosis of ESRD; [3] undergoing in-center hemodialysis for at least six months (to ensure they had moved beyond the initial adjustment phase); and [4] proficiency in English. Patients with significant cognitive impairment or an active psychiatric crisis, as noted in their medical chart, were excluded.

The lead researcher, in coordination with unit nurses, approached eligible patients to introduce the study. Those interested were provided with a detailed information sheet, and written informed consent was obtained from all participants prior to their interviews. Ethical approval was granted by the University Hospital's Institutional Review Board (Ref: #2023-BIO-087).

A total of 25 participants were enrolled. Recruitment ceased at this point as data saturation was achieved, whereby subsequent interviews yielded no new substantive themes relevant to the research question.

Data Collection

Data were collected through in-depth, semi-structured interviews. This method allows for flexibility to explore emergent topics in depth while ensuring key areas of inquiry are covered across all participants [10]. An interview guide was developed based on a review of the existing literature and consultation with a nephrology clinical nurse specialist. The guide covered several key domains:

- **Initial Experiences:** "Can you tell me about the time leading up to starting dialysis and your first few sessions?"
- **Impact on Daily Life:** "How has dialysis changed your daily routines, your work, or your family life?"
- **Physical and Emotional Experience:** "What is it like for you physically and emotionally during and after a dialysis session?"
- **Social and Relational World:** "How have your relationships with family and friends been affected?"
- **Coping and Meaning-Making:** "What helps you get through this? How do you make sense of this experience in your life?"

Interviews were conducted in a private room at the dialysis clinic, either before or after a treatment session, based on participant preference and energy levels. Each interview lasted between 45 and 75 minutes. With permission, all interviews were audio-recorded and subsequently transcribed verbatim by a professional transcription service. Field notes were also taken immediately after each interview to capture contextual observations and initial reflections.

Data Analysis

The transcribed data were analyzed using inductive thematic analysis, following the six-phase process outlined by Braun and Clarke [11]: [1] familiarization with the data, [2] generating initial codes, [3] searching for themes, [4] reviewing themes, [5] defining and naming themes, and [6] producing the report.

The analysis was primarily conducted by the lead researcher. To enhance trustworthiness and reduce analytic bias, a coding framework was developed and then reviewed and discussed with two other members of the research team. This process of peer debriefing helped to refine the themes and ensure they were firmly grounded in the data. Data management and coding were facilitated using NVivo 12 software.

Trustworthiness

Several strategies were employed to ensure the rigor and trustworthiness of the study [12]. Credibility was established through prolonged engagement with the data, peer debriefing among the research team, and member checking, where a summary of initial findings was presented to a subset of participants for confirmation. Dependability was addressed by maintaining a detailed audit trail of all research decisions and the analytic process. Thick, descriptive quotes are provided in the results to allow readers to assess the transferability of findings to other contexts.

Participant Characteristics

The 25 participants (14 male, 11 female) had a mean age of 58.4 years (range: 29–82). The mean time on dialysis was 4.2 years (range: 8 months to 11 years). The sample was ethnically diverse, reflecting the clinic's population.

Results

The analysis of participants' narratives revealed the dialysis journey to be a profound and multi-faceted experience. The essence of this experience was captured in four overarching themes, each with several sub-themes, which are detailed below with illustrative participant quotes. Pseudonyms are used throughout to protect confidentiality.

Theme 1: Loss of Autonomy and Identity

This theme encapsulates the pervasive sense of losing control over one’s life and the erosion of a pre-dialysis identity. The rigid, non-negotiable schedule of dialysis was described as a master that dictated all aspects of existence.

Sub-theme 1.1: The Tyranny of the Schedule: Participants consistently described the dialysis regimen as an all-consuming force. It dictated their weekly structure, making long-term planning impossible and rendering spontaneous activities a thing of the past.

- **Quote (David, 62):** "Your life is not your own. It belongs to the machine, to the clinic. Tuesday, Thursday, Saturday—everything revolves around that. You can't just decide to go visit your grandkids for the weekend. You're a prisoner of a schedule."

- **Quote (Maria, 45):** "I had to quit my job. You can't hold down a career when you're exhausted three days a week and have to be hooked up to a machine for four hours. I wasn't a teacher anymore; I was just a patient."

Sub-theme 1.2: Erosion of Self: Many participants expressed a feeling of no longer recognizing themselves. They grieved the loss of their former, productive selves—the worker, the caregiver, the vibrant friend—and struggled to reconcile this with their new, patient identity defined by illness and dependency.

- **Quote (James, 71):** "I was a foreman, I told people what to do. Now I get told what to do: 'sit here,' 'don't drink that,' 'take these pills.' You go from being somebody to being a number on a chart."

- **Quote (Aisha, 29):** "It's like I'm watching my life from the outside. This isn't me. The me I know is active and healthy. This body, this tiredness, this routine. it's stolen who I am."

Theme 2: Navigating a New and Unwelcome Reality
This theme describes the arduous process of adapting to the physical demands of the treatment itself and the stringent lifestyle modifications required to stay healthy enough for dialysis to work.

Sub-theme 2.1: The Physical Toll of Treatment: The dialysis session was not a passive experience. Participants described it as a draining and often painful ordeal, followed by a "washout" period of profound fatigue.

- **Quote (Linda, 53):** "The headaches, the cramping. sometimes my blood pressure drops and I get so dizzy. You just have to lie there and endure it. Then you go home and sleep for the rest of the day. That whole day is just. gone."

- **Quote (Frank, 82):** "You feel like a piece of meat being processed on a factory line. Needles in, blood out, clean it, put it back in. It's brutal."

Sub-theme 2.2: The Constant Vigilance of Dietary and Fluid Restrictions: Managing fluid intake and a renal diet was described as one of the most challenging and relentless aspects of life on dialysis. It was a constant source of mental energy and deprivation.

- **Quote (Chloe, 38):** "I dream about a big glass of ice water. It's all you think about. You have to measure everything, weigh yourself three times a day. A banana or a potato can literally kill you. How do you live when food is your enemy?"

- **Quote (Samuel, 60):** "Social life is over. No more beers with the guys. No more going out for dinner because you don't know what's in the sauce. You're just alone with your measured cup of water and your bland food."

Theme 3: The Dialysis Unit as a Dual Space
The dialysis clinic itself was a powerful and ambivalent environment, perceived simultaneously as a place of salvation and a site of trauma and community.

Sub-theme 3.1: Lifeline and Prison: There was a universal acknowledgment that the unit and the staff were keeping them alive, fostering feelings of gratitude. Yet, this was tightly interwoven with feelings of dread and entrapment associated with the physical space.

- **Quote (Robert, 55):** "This chair is my lifeline. I know that. Without it, I'm dead. But God, I hate this chair. I hate this room. The smell, the sound of the machines. it's a constant reminder that you're sick."

- **Quote (Nurse comment from field notes):** Participants often expressed deep affection and gratitude for their nurses, who were seen as their primary advocates and sources of human connection within the clinical environment.

Sub-theme 3.2: A Community of Shared Suffering: The unit fostered a unique, involuntary community. Bonds formed between patients provided crucial emotional support and a sense of being understood in a way that outsiders could not comprehend. However, this community was also a source of vicarious trauma, as patients witnessed the decline and death of their "dialysis buddies."

- **Quote (Patricia, 67):** "We're a family here. We know what each other is going through. We complain together, we joke about it. you can't talk to your healthy friends about this, they don't get it."

- **Quote (Mark, 49):** "The hardest part is when a chair is empty. You don't have to ask. You know. It messes with your head. You wonder if you're next."

Theme 4: Psychological Turbulence and Existential Uncertainty
This final theme delves into the profound internal struggle, encompassing mental health challenges and a constant confrontation with mortality and an uncertain future.

Sub-theme 4.1: The Weight of Anxiety and Depression: Feelings of sadness, worry, and fear were pervasive. Anxiety often centered on the treatment itself (e.g., "will I cramp today?") and long-term health outcomes. Apathy and depression were common, linked to the relentless and draining nature of the journey.

- **Quote (Susan, 59):** "Some days the depression is a physical weight, and you can't get out of bed. You think, 'what's the point?' You're just living to go to dialysis."

- ***Quote (Ben, 63):** "I'm always waiting for the other shoe to drop. Is my potassium too high? Is my fistula going to last? It's a low-grade panic that never really goes away."*

Sub-theme 4.2: A Future on Hold: Participants described living in a state of suspended animation. Long-term goals, dreams of retirement, and travel plans were indefinitely postponed. Life was lived in three-day cycles between

treatments, with a profound sense of uncertainty about what the future held, including the prospect of transplantation or death.

- ***Quote (Anna, 41):** "You can't make plans. You exist in two-day increments. The day after dialysis you might feel okay, so you try to live, then the next day you're gearing up for it again. There's no 'future,' there's just the next session."*
- **Quote (George, 75):** "I don't buy green bananas anymore. It's a joke we say, but it's true. Why plan for anything? This is it. This is the rest of my life, however long that is."

Table 1: Semi-Structured Interview Guide Domains and Sample Prompts

Domain	Sample Prompts
Initial Experiences	"Walk me through the process of finding out you needed dialysis. What were your first few sessions like?"
Impact on Daily Life	"How has your typical week changed? What activities have you had to give up or modify?"
Physical & Emotional Experience	"What does a dialysis session feel like for you, both physically and emotionally? How do you feel afterward?"
Social & Relational World	"How have your relationships with family, friends, and your partner been affected?"
Coping & Meaning-Making	"What gets you through the tough days? How do you find meaning or purpose in this experience?"

Table 2: Participant Demographics (N=25)

Characteristic	Category	n	%	Mean (Range)
Age				58.4 years (29-82)
Gender	Male	14	56%	
	Female	11	44%	
Time on Dialysis				4.2 years (0.7-11)
Ethnicity	White	10	40%	
	Black/African American	8	32%	
	Hispanic/Latino	4	16%	
	Asian	3	12%	
Employment Status	Disabled/Retired due to ESRD	15	60%	
	Retired (age-related)	5	20%	
	Employed (part-time)	3	12%	
	Unemployed	2	8%	

Table 3: Overview of Major Themes and Sub-themes

Major Theme	Sub-themes	Core Concept
1. Loss of Autonomy and Identity	1.1 The Tyranny of the Schedule 1.2 Erosion of Self	The treatment regimen dictates life, leading to a loss of control and a fractured sense of identity.
2. Navigating a New Reality	2.1 The Physical Toll 2.2 Constant Vigilance	Adapting to the physical demands of treatment and the relentless burden of dietary/fluid restrictions.
3. Dialysis Unit as a Dual Space	3.1 Lifeline and Prison 3.2 Community of Suffering	The clinic is perceived as both a place of salvation and entrapment, fostering a unique, involuntary community.
4. Psychological Turbulence	4.1 Anxiety & Depression 4.2 A Future on Hold	The experience is marked by mental health struggles and existential uncertainty about the future.

Table 4: Support Systems and Coping Mechanisms Identified

Category	Specific Mechanisms Mentioned	Representative Quote
Formal Support	Nephrologists, Dialysis Nurses, Social Workers, Dietitians	*"The nurses are my angels. They explain things and actually listen."*
Informal Support	Spouse/Partner, Children, Other Family, Friends, Other Patients	*"My wife is my rock. Without her, I don't know where I'd be."*
Internal Coping	Acceptance, Focusing on Small Joys, Humor, Spiritual/Religious Faith	*"I take it one day at a time. I find joy in my garden, in a good book."*
Avoidant Coping	Isolation, Suppressing Emotions, Avoidance of Health Topics	*"I don't like to talk about it. I just put my head down and get through it."*

Table 5: Recommendations for Patient-Centered Care Derived from Findings

Area for Improvement	Specific Recommendation
Psychological Support	Integrate routine mental health screenings (e.g., for depression/anxiety) and provide on-site or readily accessible psychological counseling services.
Dietary Management	Involve dietitians in more frequent, practical, and empathetic counseling sessions, moving beyond simple restriction lists to collaborative meal planning.
Peer Support	Facilitate structured peer-mentorship programs, connecting new patients with long-term survivors who have developed effective coping strategies.
Communication & Education	Train staff on trauma-informed care and communication techniques that validate patient experiences and promote shared decision-making.
Flexibility in Care	Explore and promote, where clinically appropriate, alternative treatment modalities (e.g., home dialysis) to increase patient autonomy and quality of life.

Conclusions

This qualitative study illuminates the profound and multifaceted nature of the dialysis journey, revealing it to be far more than a mere medical procedure. For patients, it represents a fundamental biographical disruption characterized by a pervasive loss of autonomy and identity, as the rigid treatment schedule usurps control over their lives. Patients must navigate a new and unwelcome reality of physical suffering and relentless dietary vigilance. The dialysis unit itself exists as a dual space, simultaneously a lifeline and a prison, fostering a unique community bound by shared suffering. Underpinning this entire experience is significant psychological turbulence and existential uncertainty about the future. These findings underscore that the clinical management of ESRD must be integrated with robust psychological and social support systems. A truly patient-centered model of care must move beyond biochemical parameters to address the holistic lived experience, empowering patients and helping them reconstruct a meaningful life amidst the constraints of their treatment.

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