Patient Preference and Adherence

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ORIGINAL RESEARCH

Understanding Patients' Experiences and Adherence Challenges with Dietary and Fluid Restriction in End-Stage Kidney Disease: A Qualitative Study

Yunyun Liao[1], Cheng Lu[1], Zhiming Shuai[2], Qing Zhu[1], Miao Zuo[1], Ling Liu[1]

[1]Department of Nephrology, Changde Hospital, Xiangya School of Medicine, Central South University (The First People's Hospital of Changde City), Changde, Hunan Province, People's Republic of China; [2]Department of Nursing, Changde Hospital, Xiangya School of Medicine, Central South University (The First People's Hospital of Changde City), Changde, Hunan Province, People's Republic of China

Correspondence: Ling Liu, Department of Nephrology, Changde Hospital, Xiangya School of Medicine, Central South University (The First People's Hospital of Changde City), Changde, Hunan Province, People's Republic of China, 415003, Tel +86 13575205001, Email Ll198607@outlook.com

Purpose: Dietary and fluid restrictions are essential for individuals with end-stage kidney disease across treatment modalities, including hemodialysis, peritoneal dialysis, and non-dialysis management. However, adherence to these restrictions remains sub-optimal, and limited evidence exists regarding how individuals across different treatment stages interpret and manage these requirements in daily life. This study aimed to explore patients' lived experiences of dietary and fluid restrictions across these groups and to identify factors associated with adherence behaviors.

Methods: A descriptive qualitative study was conducted between April and May 2024 in China. Six focus group interviews were held with 40 individuals with ESKD, including 14 receiving hemodialysis, 14 undergoing peritoneal dialysis, and 12 managed without dialysis, aged 23–76 years. All interviews were audio-recorded, transcribed verbatim, and analyzed inductively using thematic analysis to identify key themes and subthemes.

Results: Six themes and 14 subthemes were identified and organized using the Health Belief Model: perceived susceptibility (interpreting the absence of symptoms as low risk, optimistic bias); perceived severity (experiencing physical discomfort and functional limitation, anticipating burden on family and daily life); perceived benefits (perceiving health and economic benefits, strengthening responsibility and sense of control); perceived barriers (experiencing psychological burden and behavioral conflict, navigating social and situational constraints, facing information complexity and uncertainty); self-efficacy (modifying daily dietary habits, emphasizing the role of self-discipline, using monitoring and adjustment strategies); and cues to action (responding to health deterioration as a turning point, drawing on multiple sources of support).

Conclusion: Adherence to dietary and fluid restrictions in end-stage kidney disease is shaped by patients' interpretations of risk, embodied and social experiences, and negotiation of daily dietary demands. These processes occur within cultural and informational contexts where emotional burden, uncertainty, responsibility, and social support interact. Understanding these mechanisms may inform more patient-centred dietary care.

Keywords: end-stage kidney disease, dietary adherence, fluid restriction, qualitative study, health belief model

Introduction

End-stage kidney disease (ESKD) has become a major public health challenge worldwide, with both incidence and prevalence continuing to rise, placing an increasing economic burden on healthcare systems.[1] As of December 2022, data from China's National Renal Data System indicate that more than one million patients receiving dialysis were registered in mainland China. Among them, 844,265 were undergoing hemodialysis (including 156,645 newly initiated cases), while 140,544 were receiving peritoneal dialysis (with 20,800 new cases reported).[2]

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Management of ESKD typically involves kidney replacement therapy, including hemodialysis, peritoneal dialysis, and kidney transplantation,[3] as well as conservative (non-dialysis) management.[4] Patients may progress from non-dialysis management to dialysis, either peritoneal dialysis (PD) or hemodialysis (HD). However, long-term PD may be limited by complications such as ultrafiltration failure, recurrent peritonitis, and progressive structural changes in the peritoneal membrane, often necessitating transition to HD.[5] Across treatment pathways, management strategies emphasize dietary and fluid control to slow the decline in renal function, maintain metabolic stability, alleviate uremic symptoms, and improve health-related quality of life.[6] Regardless of modality, adherence to dietary and fluid restrictions remains a cornerstone of ESKD management, yet poses considerable challenges for many patients.[7] Given the extensive and complex requirements, the diet for individuals with ESKD is widely regarded as one of the most restrictive therapeutic diets.[8]

Dietary recommendations for ESKD include limiting salt and fat intake, restricting phosphorus, controlling potassium, and carefully managing fluid intake.[9] Potassium intake should be individualized according to clinical conditions.[9] Daily salt intake is generally recommended to be below 5 g; for patients with edema, it should be reduced to less than 3 g, and in cases of severe edema, a salt-free (sodium <1000 mg) or low-sodium diet (sodium <500 mg) may be required.[9] Fluid intake should be adjusted based on urine output and dialysis ultrafiltration to maintain balance.[9] However, these recommendations differ in important ways from general dietary guidance for healthy populations. The Chinese Dietary Guidelines emphasize reduced salt and oil intake, regular meals, and adequate hydration.[10] For example, adults with low physical activity are advised to consume approximately 1500–1700 mL of water per day under mild climatic conditions.[10] In addition, relatively higher potassium intake is recommended for healthy adults with normal kidney function.[11] These discrepancies may create practical challenges for individuals with ESKD, particularly when sharing meals with others whose dietary patterns follow general recommendations.

In the Chinese cultural context, dietary practices are deeply embedded in social and relational structures. Meals are typically organized around shared dishes rather than individual portions, and eating together serves important functions in maintaining interpersonal relationships and family cohesion.[12] As a result, dietary and fluid restrictions may extend beyond individual self-management and become socially negotiated practices. Patients may face difficulties adhering to restrictions in shared meal settings, where refusing food or modifying eating behaviors can carry relational implications, such as appearing impolite or disrupting social harmony. These culturally embedded practices may therefore shape how dietary recommendations are interpreted and enacted in daily life.[13]

Dietary and fluid requirements also vary depending on the type of kidney replacement therapy. For instance, patients undergoing hemodialysis are typically required to restrict potassium intake, whereas those receiving peritoneal dialysis may have greater flexibility.[14] Despite these tailored recommendations, adherence remains suboptimal. A systematic review and meta-analysis reported nonadherence rates ranging from 47.3% to 72.5% for dietary restrictions and from 50% to 70.7% for fluid restrictions.[15] Inadequate intake of high-quality protein and excessive consumption of phosphorus, sodium, potassium, lipids, and fluids may lead to complications, reduce quality of life, and adversely affect long-term survival.[16]

Nonadherence to prescribed dietary and fluid restrictions is therefore a significant clinical concern that limits the effectiveness of routine therapies.[15] It is associated with electrolyte imbalance, fluid overload, exacerbation of symptoms, reduced quality of life, repeated hospitalization, increased healthcare costs, and higher mortality.[17–19] Moreover, long-term adherence requires substantial adjustments to daily eating habits and social routines, including dining out and social interactions.[20] These changes may generate emotional distress and lead patients to perceive restrictions as burdensome, making sustained adherence difficult.[20] In addition, due to the limited availability of renal dietitians, nephrology nurses often assume primary responsibility for providing dietary education in clinical settings.[21]

A better understanding of how individuals with ESKD experience dietary and fluid restrictions is essential for supporting effective self-management. Existing qualitative studies have predominantly focused on patients undergoing hemodialysis,[22–24] with comparatively limited attention to those receiving peritoneal dialysis or conservative (non-dialysis) management. However, these groups differ in treatment context, symptom experience, and daily routines, which may shape how dietary and fluid restrictions are perceived and enacted. For example, hemodialysis is typically center-based and intermittent, whereas peritoneal dialysis is home-based and requires continuous self-management.

Patients receiving conservative management may experience fewer immediate symptoms, which could influence their perceptions of susceptibility and severity. These differences suggest that findings derived from hemodialysis populations may not be directly transferable to other groups.

Furthermore, prior qualitative studies have largely described patients' experiences without systematically examining how these perceptions interact to shape behavior.[24,25] As a result, the mechanisms underlying adherence remain insufficiently theorized. The Health Belief Model (HBM) provides a useful framework for addressing this gap by examining how perceived susceptibility, severity, benefits, and barriers—together with cues to action and self-efficacy—shape health-related behaviors.[26] This model has been widely applied in health education and behavioral interventions across chronic conditions,[27,28] with evidence showing that HBM-based interventions can improve adherence to treatment regimens, particularly in conditions such as diabetes.[29]

This study therefore aims to explore the experiences of dietary and fluid restrictions among individuals with ESKD, including those undergoing hemodialysis, peritoneal dialysis, and non-dialysis management, using the HBM as an analytical framework. By doing so, it seeks to generate a more theoretically informed understanding of adherence behaviors and to inform tailored support strategies for clinical practice.

Materials and Methods

Study Design

This study adopted a qualitative descriptive design using focus groups. The qualitative descriptive approach is widely used to gather insights from key informants on healthcare issues that are not well understood.[30,31] This design was considered appropriate for providing a comprehensive description of participants' perceived experiences with dietary and fluid restrictions among patients with ESKD. Focus groups facilitated data collection by encouraging open information exchange, resulting in richer data and deeper insights into the topic.

Study Setting

This study was performed in The First People's Hospital of Changde City, Changde, China, which has the largest nephrology department in the Northwestern Hunan region and is designated as a key specialty in Changde City. The department has 51 inpatient beds and an annual outpatient volume of nearly 25,000 visits.

Participants

The eligibility criteria for participants were as follows: age ≥18 years, diagnosis of ESKD for more than 3 months, and the ability to communicate verbally. The diagnosis was confirmed via electronic medical records. Participants who were critically ill (requiring cardiac monitoring), had mental or cognitive disorders, or had a history of kidney transplantation were excluded.

Sampling and Recruitment

This study employed purposive sampling until data saturation was achieved. Participants were recruited through referral by practicing nurses in the nephrology inpatient and outpatient departments, as well as through study recruitment posters displayed in outpatient clinics, inpatient wards, and hemodialysis centers. The posters provided brief information about the study purpose and included contact details for the research team, allowing interested individuals to contact the researchers directly. Practicing nurses introduced the study to patients with ESKD who were either currently hospitalized or attending outpatient clinics. In addition, discharged patients with ESKD were contacted by phone and informed about the study. Individuals who expressed interest in participating through any of these approaches were invited to contact the first author. The first author then followed up with interested individuals by telephone to further explain the study aims and procedures. It was emphasized that participation was entirely voluntary, that there would be no penalties for declining participation, and that clinical staff would not be informed of participants' decisions.

Data Collection

The focus group interviews were conducted between April and May 2024 in a quiet room at the hospital. To promote interaction and engagement, participants were seated around an oval table The focus group interviews consisted of six groups, each with six to eight participants, organized by their type of kidney replacement therapy—hemodialysis patients, peritoneal dialysis patients, and non-dialysis patients—with participants receiving the same therapy grouped together. All focus group interviews were held in the same room and conducted at different times, as scheduled in advance.

The interview guide was developed based on a literature review and the HBM. The interview questions are detailed in Figure 1. Each focus group began with a short, structured introduction by the moderator, who explained the purpose of the research and the topics for discussion. The interviews were conducted in Mandarin. The first author, a registered nurse with 10 years of nephrology experience and qualitative research training, facilitated the focus groups. The fourth author, a specialist nurse with 12 years of experience in peritoneal dialysis and research training as part of a clinical undergraduate program, took field notes and observed the interactions within the groups. The duration of the focus group interviews ranged from 63 to 88 minutes, with a mean duration of 72.3 minutes. Each participant received compensation of 72 RMB (approximately USD $10) after the interview.

Data Analysis

The focus groups were conducted in Mandarin and audio-recorded. The audio recordings were transcribed in Mandarin using Xunfei software, and the accuracy of the transcriptions was verified by the authors (Z.Q. and L.C). Preliminary data collection and analysis occurred concurrently, with data collection continuing until saturation was reached. Content analysis was performed using a directed content analysis approach, guided by the HBM.In line with Braun and Clarke's six-step approach,[32,33] three authors (L.Y., Z.Q., and L.C.) independently analyzed the transcripts by reading them line by line and generating initial codes in Mandarin. Constant comparative analysis was used to ensure that all codes were consistently defined and applied across the transcripts. The first three transcripts were independently coded by L.Y., Z.Q., and L.C., who then deliberated to form a preliminary coding framework. This process was repeated with additional

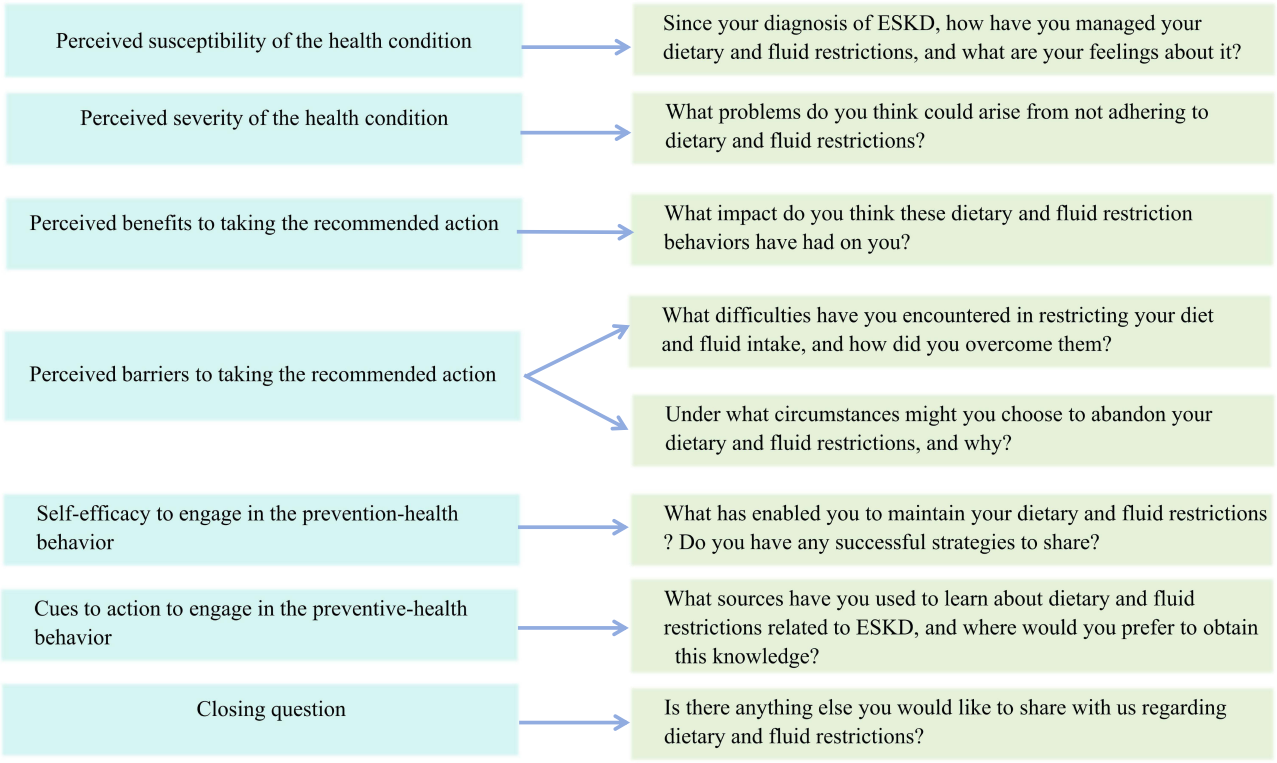

Figure 1 HBM based interview questions.

transcripts, refining and reducing the number of categories and subcategories by grouping similar codes together. Other authors reviewed samples of the coded transcripts to examine the coding. All authors discussed the assigned codes multiple times until a consensus was reached. Once the final coding framework was developed, the remaining transcripts were coded. All transcripts were then independently coded by L.Y., Z.Q., and L.C. No new data emerged during the last two interviews, indicating that sufficient data had been obtained to fully describe the topic. Final themes were constructed using an inductive approach. Thematic analysis was conducted manually, without the use of software. The HBM was employed to group the themes, connecting the findings to the existing literature and conceptual framework. This framework was refined through discussions among all authors, with modifications made and a consensus reached over multiple meetings.

Ethical Considerations

Ethical approval was obtained from the Clinical Medicine Research Ethics Committee of The First People's Hospital of Changde City (No. 2024–034-01). All participants provided written informed consent prior to participation. Informed consent included permission for the publication of anonymised responses and direct quotes. Participants were informed that participation was voluntary and that they could withdraw from the study at any time without providing a reason. To ensure anonymity and confidentiality, individual codes were used in place of participants' names during data analysis and reporting. The study was conducted in accordance with the Declaration of Helsinki.

Rigour

During analysis, coding was conducted independently by two researchers, followed by regular discussions to compare interpretations and resolve discrepancies. Differences in coding were not treated as errors but as opportunities to refine the coding framework and deepen interpretation. Data collection and analysis were conducted concurrently. Field notes were taken during the focus group interviews to capture contextual and non-verbal information, which informed subsequent coding and interpretation. Audio recordings were transcribed verbatim, and transcripts were checked against recordings for accuracy. An audit trail was maintained throughout the study, documenting key analytical decisions, code development, and theme refinement. This process allowed the research team to trace how interpretations evolved over time. Reflexivity was considered throughout the research process. The first author, who has a clinical background in nephrology nursing, was aware that prior professional experience might shape data interpretation, particularly in relation to assumptions about patient adherence. To address this, interpretations were regularly discussed within the research team, which included members with different levels of clinical and research experience. To support readers in assessing the relevance of the findings, detailed descriptions of the study context, participant characteristics, and recruitment processes are provided.

Results

Characteristics of Participants

A total of 44 patients with ESKD were invited to participate; 4 declined, resulting in 40 participants who completed the interviews. Participants ranged in age from 23 to 76 years, with slightly more female (n = 21) than male (n = 19) participants. Nine participants had an education level of primary school or below, 17 had a junior school education, and 14 had a senior high school education or higher. Participants were receiving different types of kidney replacement therapy: hemodialysis (n = 14), peritoneal dialysis (n = 14), and non-dialysis (n = 12). The duration of dialysis for hemodialysis and peritoneal dialysis participants ranged from 1 to 168 months. Participants' sociodemographic characteristics are summarized in Table 1.

No substantial differences in themes were observed across non-dialysis, peritoneal dialysis, and hemodialysis groups; therefore, the findings are presented as an integrated analysis. Six overarching themes and fourteen subthemes were identified (Figure 2): perceived susceptibility (interpreting the absence of symptoms as low risk, optimistic bias); perceived severity (experiencing physical discomfort and functional limitation, anticipating burden on family and daily life); perceived benefits (perceiving health and economic benefits, strengthening responsibility and sense of control);

Table 1 Demographics of Participants (N = 40)

Participant	Age	Gender	Educational Level	Kidney Replacement Therapy	Disease Staging	Months on Dialysis	Occupation	Co-Morbidities
F1N1	62	Female	Junior school	Peritoneal dialysis	5	6	Retirement	Diabetes, Hypertension, CVD
F1N2	49	Female	Junior school	Peritoneal dialysis	5	12	Self-employed individual	Hypertension, CVD
F1N3	48	Male	Junior school	Peritoneal dialysis	5	1	Unemployed	Hypertension
F1N4	36	Male	Junior school	Peritoneal dialysis	5	5	Unemployed	Hypertension, CVD
F1N5	34	Female	≥ College	Peritoneal dialysis	5	12	Self-employed individual	Hypertension
F1N6	55	Male	Junior school	Peritoneal dialysis	5	11	Unemployed	Hypertension, CVD
F1N7	23	Female	≥ College	Peritoneal dialysis	5	19	Unemployed	/
F2N1	63	Male	Junior school	Hemodialysis	5	120	Retirement	Hypertension
F2N2	49	Male	≥ College	Hemodialysis	5	72	Unemployed	Hypertension
F2N3	64	Female	Primary school	Hemodialysis	5	60	Retirement	Diabetes, Hypertension
F2N4	66	Male	Senior high school	Hemodialysis	5	168	Retirement	CVD
F2N5	44	Male	Senior high school	Hemodialysis	5	60	Unemployed	Hypertension, CVD
F2N6	41	Male	Junior school	Hemodialysis	5	84	Unemployed	Hypertension
F2N7	51	Male	Primary school	Hemodialysis	5	48	Unemployed	Hypertension
F2N8	58	Male	Junior school	Hemodialysis	5	48	Retirement	Hypertension, CVD
F3N1	62	Female	Senior high school	Non-dialysis	5	/	Self-employed individual	Hypertension
F3N2	59	Female	Junior school	Non-dialysis	5	/	Unemployed	Diabetes, Hypertension
F3N3	38	Female	≥ College	Non-dialysis	5	/	Company employee	Hypertension, CVD
F3N4	42	Female	Senior high school	Non-dialysis	5	/	Company employee	Diabetes, Hypertension, CVD
F3N5	55	Female	Primary school	Non-dialysis	5	/	Self-employed individual	Hypertension
F3N6	76	Male	Junior school	Non-dialysis	5	/	Retirement	/
F4N1	52	Female	Senior high school	Peritoneal dialysis	5	45	Unemployed	Hypertension, CVD
F4N2	52	Female	Junior school	Peritoneal dialysis	5	20	Unemployed	Diabetes, Hypertension
F4N3	31	Female	≥ College	Peritoneal dialysis	5	11	Unemployed	Hypertension
F4N4	53	Female	Primary school	Peritoneal dialysis	5	25	Self-employed individual	Hypertension
F4N5	62	Male	Primary school	Peritoneal dialysis	5	19	Unemployed	Hypertension
F4N6	49	Male	Junior school	Peritoneal dialysis	5	26	Unemployed	Hypertension

(*Continued*)

Table 1 (Continued).

Participant	Age	Gender	Educational Level	Kidney Replacement Therapy	Disease Staging	Months on Dialysis	Occupation	Co-Morbidities
F4N7	56	Male	< Primary school	Peritoneal dialysis	5	42	Unemployed	Hypertension, CVD
F5N1	59	Female	Junior school	Hemodialysis	5	60	Unemployed	Hypertension
F5N2	59	Female	Primary school	Hemodialysis	5	66	Retirement	Hypertension
F5N3	37	Male	Junior school	Hemodialysis	5	60	Unemployed	Hypertension
F5N4	63	Male	< Primary school	Hemodialysis	5	96	Unemployed	Diabetes, Hypertension
F5N5	37	Male	Junior school	Hemodialysis	5	60	Unemployed	Hypertension
F5N6	34	Female	Junior school	Hemodialysis	5	10	Unemployed	Hypertension, CVD
F6N1	50	Female	Primary school	Non-dialysis	5	/	Unemployed	Hypertension, CVD
F6N2	66	Female	Senior high school	Non-dialysis	5	/	Retirement	Diabetes, Hypertension, CVD
F6N3	48	Female	Senior high school	Non-dialysis	5	/	Company employee	Diabetes, Hypertension
F6N4	52	Male	Senior high school	Non-dialysis	5	/	Unemployed	Hypertension, CVD
F6N5	57	Male	Junior school	Non-dialysis	5	/	Unemployed	Hypertension
F6N6	54	Female	Senior high school	Non-dialysis	5	/	Unemployed	Diabetes, Hypertension

perceived barriers (experiencing psychological burden and behavioral conflict, navigating social and situational constraints, facing information complexity and uncertainty); self-efficacy (modifying daily dietary habits, emphasizing the role of self-discipline, using monitoring and adjustment strategies); and cues to action (responding to health deterioration as a turning point, drawing on multiple sources of support).

Theme 1: Perceived Susceptibility

Participants did not consistently perceive themselves as being at risk from dietary and fluid non-adherence. Susceptibility was often interpreted through immediate experience and personal judgment, which led some to minimize or distance perceived risk.

Interpreting the Absence of Symptoms as Low Risk

For some participants, the absence of noticeable symptoms or complications reduced their sense of vulnerability and weakened the perceived need for strict adherence.

> I don't seem to have many issues; I can drink, eat, and sleep just fine. It does not appear to have a significant impact on my condition. (F1N3)

> I am already undergoing hemodialysis, so I don't strictly control my diet. I know I shouldn't consume certain foods, yet I still do. I believe it doesn't have a significant impact on me. (F2N7)

Optimistic Bias

The perception of risk may be influenced by unrealistic optimism regarding one's own risks. Some participants believed that their individual situation was different and that they were less likely to experience negative consequences.

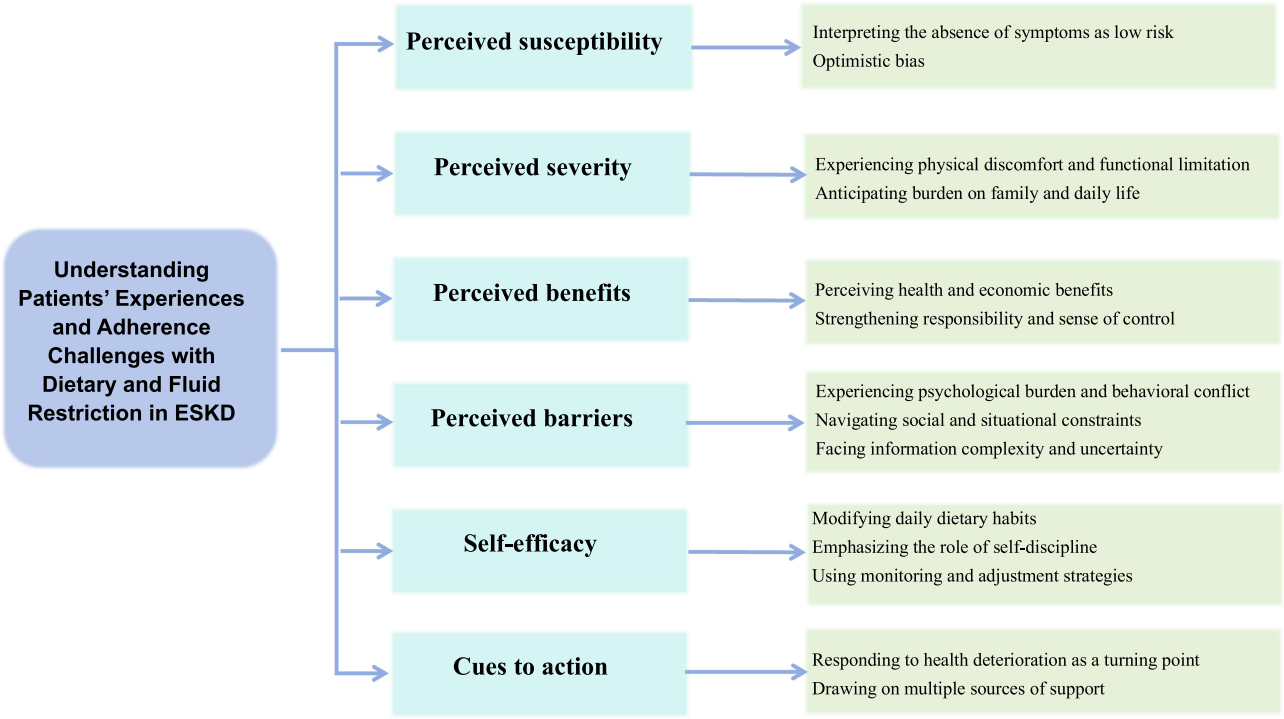

Figure 2 Understanding Patients' Experiences and Adherence Challenges with Dietary and Fluid Restriction in ESKD.

I don't see myself as a patient. I eat whatever I want. sometimes I just forget that I'm a patient. (F4N4)

Being young is an advantage. I don't want to impose any restrictions on my diet or water intake. (F5N5)

Theme 2: Perceived Severity

Participants described non-adherence as having tangible consequences. Perceived severity was shaped both by bodily experiences and by concerns about its broader impact on daily life and family.

Experiencing Physical Discomfort and Functional Limitation

Physical symptoms were frequently described as direct consequences of non-adherence and were closely linked to disruptions in daily functioning.

If you can't control it, you'll cramp, and I can't handle it. The feeling of cramping is worse than dying. (F2N5)

My legs are still a bit swollen, and I don't have the strength to walk as I used to… after just 7,000 steps, I feel exhausted. (F1N1)

Anticipating Burden on Family and Daily Life

Participants also described how worsening health could lead to increased financial strain, dependence, and disruption to family life.

At first, I didn't take it seriously. The more I ignored the dietary and fluid restrictions, the more problems I had, and eventually, it led to me having to be hospitalized every month. (F1N2)

Since my diagnosis, I have gone through the stages from not requiring dialysis, to peritoneal dialysis, and now to hemodialysis. I can't work, so we rely entirely on my husband's income. If my condition worsens because I don't follow the dietary and fluid restrictions, it will place additional financial strain on my family and may even lead to family conflicts. (F2N5)

Theme 3: Perceived Benefits

Participants described adherence as beneficial in multiple ways, including improving health outcomes and supporting a sense of responsibility toward themselves and their families.

Perceiving Health and Economic Benefits

Adherence was commonly associated with improved physical condition, more stable indicators, and reduced healthcare-related burden.

> If you don't control your diet and fluid intake, you won't live long. I have children and a husband at home, and I still want to spend more years with them. (F2N2)

> I don't want to burden my daughter with additional financial costs. She's already doing so much for me, and I try to follow the dietary restrictions to slow the progression of my illness. (F4N7)

> By controlling my salt intake, my mental state has improved compared to before. (F6N4)

Strengthening Responsibility and Sense of Control

Adherence was also described as a way of taking responsibility and maintaining a sense of control over one's condition.

> By sticking to the restrictions, I feel more in control of my health. (F3N3)

> When I follow the dietary restrictions, I feel like I'm doing something to help myself. Seeing positive changes in my health makes it feel worthwhile. (F4N3)

Theme 4: Perceived Barriers

Participants described multiple challenges that made adherence difficult, including emotional strain, social expectations, and difficulties in understanding dietary information.

Experiencing Psychological Burden and Behavioral Conflict

Long-term adherence was often described as restrictive and emotionally taxing, creating tension between health requirements and personal preferences.

> I feel like a burden when I can't eat what others are eating. Sometimes I feel guilty because my family has to adjust their meals for me. I wish I didn't have to be so picky about everything. (F3N1)

> I always have to consider what I can and cannot eat, and after a while, it gets tiring. It makes me feel like I'm missing out on so much, especially when everyone else is enjoying themselves. (F6N5)

Navigating Social and Situational Constraints

Social interactions, particularly family gatherings and shared meals, were described as situations in which adherence became more difficult.

> I understand that I need to control myself, but sometimes I can't. During holidays, when I go back to my parents' house, relatives keep saying, 'Try a bit of this, try a bit of that,' and before I realize it, I've already eaten too much. (F2N5)

> Before I got sick, I used to love inviting friends out to eat, hang out, and drink together. But now, I'm afraid to go out with them because sometimes I can't control myself and end up eating things I shouldn't. (F4N5)

Facing Information Complexity and Uncertainty

Participants reported confusion when trying to follow dietary recommendations, particularly when information sources were inconsistent or difficult to understand.

> Although we've received more professional advice from medical experts, it's difficult to tell what's true or false on the internet these days. This sometimes leads us to make mistakes and eat things we shouldn't, especially when influenced by misleading information in short videos. It would be great to have one-on-one guidance. (F1N5)

> In the early stage of my illness, I didn't know what I could eat and what I couldn't, or what needed to be controlled. The information provided by doctors and nurses, other patients, and what I found on my phone was sometimes contradictory and difficult to understand. As time went on, I gradually learned more. I have also seen some new patients take things to the extreme —eating almost nothing and ending up severely malnourished. (F2N4)

Theme 5: Self-Efficacy

Participants described varying levels of confidence in their ability to adhere, with some demonstrating gradual adaptation and increasing self-management capacity.

Modifying Daily Dietary Habits

Some participants reported making practical changes to their daily behaviors in order to meet dietary and fluid requirements.

> I used to braise chicken with soy sauce and other seasonings, but now I always poach it. (F1N1)

> I no longer drink alcohol. I also no longer eat barbecue… gradually learning to control myself. (F1N7)

Emphasizing the Role of Self-Discipline

While family support and supervision are helpful for managing dietary and fluid restrictions, participants highlighted self-discipline as essential for maintaining adherence, particularly in situations where external supervision was limited.

> To live well in the future without more complications, self-discipline is something we must learn. (P1N5)

> I used to do well under my family's supervision, but when they were away on business or not living with me for other reasons, I didn't control my diet and fluid intake as well. I think self-discipline is essential. Stay positive and don't fool yourself. (P6N6)

Using Monitoring and Adjustment Strategies

Some participants described adjusting their intake based on ongoing monitoring of their physical condition, as well as using practical strategies to manage their diet and fluid intake.

> When it comes to water intake, I have a small trick: I use the smallest measuring cup and generally limit myself to around 400 milliliters a day. If I get extremely thirsty, I sometimes chew on a bit of ice. (F4N6)

> I weigh myself every morning on dialysis days. If my weight gain is high, I try to drink less water and eat less. If my weight is within range, I allow myself to eat and drink more. But I generally avoid stir-fried dishes and stick to steamed food. That's how I manage it. (F5N2)

Theme 6: Cues to Action

Participants described specific events and sources of support that prompted or reinforced adherence behaviors.

Responding to Health Deterioration as a Turning Point

Experiencing complications or worsening health was described as a key moment prompting stricter adherence.

> I didn't restrict my water intake and drank quite a lot, which led to heart failure within a year. (F1N2)

> Once you know you've developed complications, you'll follow any doctor's prescription… You won't turn back until you hit a brick wall. (F3N2)

Drawing on Multiple Sources of Support

Participants described drawing on multiple sources of support to manage dietary and fluid restrictions, including health education from medical staff, experience sharing among patients, family involvement, as well as information from videos, TV programs, and online searches.

> I usually communicate with nurses and doctors in specialist clinics, and I often follow the hospital's official account for updates. I also check the account for relevant information. (F1N7)

> I enjoy watching TV programs that discuss nutrition and health tips. They help me feel more confident in making the right choices about my diet and fluid intake. (F2N4)

> My family reminds me from time to time and shares relevant information with me. When we eat together, they also keep an eye on me—my siblings and my husband all help supervise what I eat. I know I have to control myself. I'm really grateful for the support my family has given me throughout this illness. (F2N8)

> When I undergo dialysis, doctors and nurses are usually very busy, and sometimes I cannot fully understand what they are saying. I often chat with other patients, discussing how to manage diet and fluid restrictions—such as controlling water intake. I also watch short videos and read related articles online that explain dietary tips and the importance of fluid control. This is easier to understand and remember than some of the complex instructions given by doctors. (F5N3)

Discussion

Using a qualitative approach, this study explored how individuals with ESKD make sense of and manage dietary and fluid restrictions in everyday life. Participants' accounts point to a dynamic process in which adherence is shaped by the ways risks are perceived, consequences are experienced, and constraints are negotiated in daily contexts. Guided by the HBM, six interrelated themes were identified, capturing these processes across perceptions of susceptibility and severity, evaluations of benefits and barriers, as well as evolving self-efficacy and cues to action. While prior qualitative research has largely focused on hemodialysis populations, this study extends existing work by including individuals undergoing peritoneal dialysis and conservative (non-dialysis) management, groups that have received comparatively less attention despite differences in dietary and fluid restriction requirements. No substantial thematic differences were observed across treatment groups. This should be interpreted with caution, as many participants undergoing dialysis had previously experienced non-dialysis stages. Rather than indicating an absence of meaningful variation, the findings may reflect shared and evolving experiential processes across the illness trajectory, suggesting that adherence is shaped not only by treatment modality but also by patients' cumulative experiences of managing restrictions over time.

Participants' accounts of perceived susceptibility indicated that risk was often interpreted through immediate bodily experience rather than abstract medical knowledge. In the absence of noticeable symptoms, some participants described themselves as being "fine," which reduced the perceived necessity of strict adherence. Others expressed a sense of personal exception, suggesting that adverse outcomes were less likely to occur to them. These patterns resonate with prior research showing that risk perception in chronic illness is frequently filtered through subjective experience rather than clinical indicators.[34] Rather than indicating a lack of knowledge, such interpretations may reflect how patients reconcile medical advice with lived experience over time.

In contrast, perceived severity was grounded more directly in embodied experience and life consequences. Participants linked non-adherence to dietary and fluid restrictions with symptoms such as cramping, fatigue, and functional limitation, as well as broader disruptions including repeated hospitalizations, financial strain, and increased dependence on family members. These accounts suggest that the salience of severity is often reinforced retrospectively, particularly when deterioration or complications occur. This experiential dimension of severity has been similarly noted in prior studies, where symptom burden and life disruption shaped patients' understanding of illness seriousness.[35]

At the same time, participants articulated multiple perceived benefits of adhering to dietary and fluid restrictions, extending beyond biomedical outcomes. In addition to symptom relief and more stable clinical indicators, adherence was described as a way to maintain family roles, reduce economic burden, and sustain a sense of continuity in everyday life. Notably, several participants emphasized a growing sense of control and responsibility as they became more engaged in

managing their dietary and fluid intake. This aligns with earlier work suggesting that perceived control is closely linked to adaptive health behaviors.[36,37] In the present study, such perceptions appeared to develop gradually through lived experience, particularly when participants noticed tangible improvements associated with maintaining dietary and fluid restrictions. A survey of patients with ESKD undergoing dialysis indicated that their sense of empowerment was strengthened by understanding the clinical rationale behind lifestyle restrictions, receiving ongoing practical training, and having family support in managing their treatment regimens.[38]

Despite these perceived benefits, participants also described substantial barriers that complicated adherence in practice. These included emotional strain associated with long-term restriction, conflicts between dietary rules and personal preferences, and difficulties navigating social situations. Shared meals, in particular, emerged as a recurring challenge. In the Chinese cultural context, where communal dining is central to social interaction, dietary restriction often carried relational implications.[39] Participants described hesitating to refuse food offered by others or feeling uncomfortable explaining their condition, which sometimes led to deviations from recommended dietary practices from recommended practices. Similar tensions between social expectations and dietary adherence have been reported in previous studies.[40,41] The need to maintain adherence frequently triggered feelings of alienation, resentment, or guilt, which further undermined compliance. These findings align with prior studies,[42,43] suggesting that culturally sensitive interventions are needed to address social pressures faced by persons with ESKD.

Another prominent barrier concerned information complexity and uncertainty. Participants reported receiving dietary advice from multiple sources, including healthcare professionals, peers, and online platforms, which was not always consistent or easy to interpret. Some described confusion during the early stages of illness, while others noted that even with experience, contradictory information remained difficult to resolve. Although nephrology nurses and physicians were generally regarded as trustworthy sources, limited time for detailed guidance appeared to constrain their role. These findings echo previous literature highlighting challenges in translating dietary recommendations into actionable guidance in chronic disease management.[44] In addition, although some dialysis-related websites and online platforms provide nutrition newsletters, support groups, and social media content, these resources are often fragmented and limited in scope.[45] Taken together, the coexistence of multiple but inconsistent information sources may contribute to uncertainty in dietary decision-making. In this context, mobile health applications may offer a more integrated approach by providing real-time,[46] personalized nutritional guidance tailored to patients' changing conditions, facilitating communication with dietitians, and supporting ongoing monitoring of dietary intake and nutritional status, which may help address information-related challenges in ESKD.

Participants' accounts of self-efficacy reflected a process of gradual adaptation rather than a fixed trait. Self-efficacy, defined as an individual's belief in their ability to perform tasks and achieve desired goals,[47] was expressed through practical efforts to manage dietary and fluid intake. Some participants described modifying cooking methods, restricting specific foods, or adopting strategies to regulate fluid consumption. Self-discipline was frequently emphasized, particularly in situations where external supervision was limited. In addition, participants reported using monitoring strategies, such as tracking body weight or adjusting intake based on bodily responses, to guide daily decisions. These accounts suggest that self-efficacy in this context is closely tied to experiential learning and ongoing adjustment, rather than solely to initial confidence in one's ability to adhere. This finding complements previous research indicating that many individuals with ESKD may experience low self-efficacy due to treatment complexity, limited knowledge, psychological burden, and insufficient social support.[48,49]

The theme of cues to action further illustrates how adherence was often prompted by specific events or social influences. For many participants, health deterioration or the onset of complications served as a turning point that led to stricter adherence. In addition, participants described drawing on multiple forms of support, including guidance from healthcare providers, reminders from family members, and experience sharing with peers. Peer interaction, in particular, appeared to provide both practical strategies and emotional reassurance, helping participants navigate challenges such as food cravings or social dining. These observations are consistent with previous findings on the role of peer support in chronic disease self-management.[50,51] Family involvement was another critical element, with relatives often assisting in meal preparation, monitoring compliance, and providing emotional encouragement. Khwanchum et al[52] similarly

demonstrated that family management support programs enhanced disease knowledge and self-management skills among patients with early-stage chronic kidney disease.

Overall, the findings suggest that adherence to dietary and fluid restrictions in ESKD is not simply a matter of knowledge or motivation, but involves ongoing negotiation between medical recommendations and the realities of daily life. The six themes identified in this study correspond to key constructs of the Health Belief Model, while also highlighting how these constructs are shaped by contextual and experiential factors. Rather than operating as discrete components, perceptions of susceptibility, severity, benefits, and barriers appeared to interact dynamically, alongside evolving self-efficacy and context-dependent cues to action.

Several implications can be considered in light of these findings. First, participants' reliance on experiential cues suggests that risk communication may benefit from connecting clinical information with patients' lived experiences, particularly in the early stages of disease when symptoms are less apparent. Second, the social challenges associated with shared meals indicate the importance of considering cultural context when discussing dietary management. Third, the variability and complexity of information sources highlight the potential value of more coordinated and accessible guidance, including clearer communication and opportunities for individualized support. In addition, participants' accounts suggest that individualizing dietary management may be important for supporting adherence. Approaches that take into account patients' preferences, cultural food practices, and available resources, and that provide feasible alternatives rather than solely emphasizing restriction, may be more consistent with how patients navigate dietary decisions in everyday life. Within this context, multidisciplinary support, including input from dietitians with specialized training in nephrology, may offer additional opportunities to tailor nutritional guidance.

Limitations

First, although participants were recruited from hemodialysis, peritoneal dialysis, and non-dialysis groups, this study did not adopt a longitudinal design to examine how experiences of dietary and fluid restrictions evolve over time. Given that disease progression and treatment transitions may substantially influence patients' perceptions and behaviors, future longitudinal qualitative studies may provide a more nuanced understanding of these processes. Second, the wide range of dialysis duration among participants may have influenced the findings, as individuals at different stages of treatment may vary in their adaptation to dietary restrictions. Third, the study was conducted in a single tertiary hospital within mainland China, and the findings should therefore be interpreted in light of the specific cultural and healthcare context. In addition, voluntary participation may have introduced selection bias, and the use of focus groups moderated by healthcare professionals may have influenced participants' willingness to openly discuss non-adherent behaviors. Future research could consider larger and more diverse samples, as well as complementary quantitative or mixed-methods designs, to further examine the patterns identified in this study. Finally, it is important to note that the interpretations presented here are grounded in participants' accounts and are intended to offer a theoretically informed understanding of adherence behaviors, rather than definitive or causal explanations.

Conclusion

This study provides a qualitative understanding of how individuals with ESKD experience dietary and fluid restrictions through the HBM. Findings suggest that adherence is shaped by lived interpretations of risk, embodied and social experiences of illness, and the negotiation of competing demands in everyday dietary practices, with patterns appearing relatively consistent across treatment modalities. Dietary and fluid management was embedded in social and informational contexts, where emotional burden, cultural practices, and uncertainty intersected with perceived benefits, responsibility, and support from others. Overall, the study offers insight into how dietary restrictions are experienced and enacted in real-life settings, which may inform more context-sensitive and patient-centred nutritional care in ESKD.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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