

Experiences of Dietary Management and Social Adaptation in Young End-Stage Renal Disease Maintenance Hemodialysis Patients: A Qualitative Study

Linghan Zhou¹, Liping Kang², Dongyang Wang¹, Qingmiao Li³, Junfan Wei⁴, Mengtian Li⁵, Meng Li¹, Huawei Li¹

¹Nursing Department, The Third People's Hospital of Henan Province, Zhengzhou, People's Republic of China; ²Zhuhai Hospital of Integrated Traditional Chinese and Western Medicine, Zhuhai, People's Republic of China; ³School of Social Undertakings, Henan Normal University, Xinxiang, People's Republic of China; ⁴The Seventh Clinical Medicine College of Guangzhou University of Chinese Medicine, Shenzhen, People's Republic of China; ⁵School of Nursing, Xinxiang Medical University, Xinxiang, People's Republic of China

Correspondence: Huawei Li, Nursing Department, The Third People's Hospital of Henan Province, 198 Funiu Road, Zhongyuan District, Zhengzhou, Henan Province, 450000, People's Republic of China, Email 13700841908@qq.com

Purpose: To explore the experiences of young hemodialysis patients regarding diet therapy and social adjustment.

Methods: This study used purposive sampling to select 19 young hemodialysis patients for semi-structured interviews at a tertiary hospital in Henan Province, China. We followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines for qualitative research to ensure comprehensive reporting.

Results: We identified five topic categories: "Diet therapy perceptions", including Lack of knowledge, imprudent attitude. "Diet therapy behaviors", including Vigilant Diet, Anxiety about water, Control of salt. "Access to dietary information", including Active acquisition, Passive acquisition. Family roles", including Changes in dietary habits, Support of information, Reducing family involvement. Challenges of social adjustment", including Barriers to work, Socialization Pain Points, Emotional distress, Looking for a way out.

Conclusion: Young MHD patients recognize the importance of diet therapy and social reintegration but face barriers including knowledge gaps, inadequate support, and self-perceived burden. Key interventions should focus on: improved knowledge dissemination, optimized dietary education, nocturnal dialysis options, emotion regulation strategies, and enhancing self-efficacy. Strengthening national and societal support systems is critical for sustainable outcomes. Future research should employ longitudinal studies to track psychological adaptation and develop tailored, technology-assisted interventions for this population.

Keywords: diet therapy, social adjustment, hemodialysis, qualitative research

Introduction

Chronic kidney disease (CKD), defined as kidney dysfunction persisting >3 months,¹ progresses to end-stage kidney disease (ESKD) when glomerular filtration rate falls below 15 mL/(min·1.73 m²), necessitating renal replacement therapy (hemodialysis, peritoneal dialysis, or kidney transplantation). In 2019, an estimated 14.5 million people will be living with ESKD worldwide by 2030, as shown in the Global Kidney Health Map released by the International Society of Nephrology (ISN). According to the data of the Sixth China Chronic Disease and Risk Factor Surveillance Report, the prevalence rate of CKD among Chinese adults is 8.2%, and the prevalence rate of ESRD is 4.3% per 10,000 people.² Maintenance hemodialysis (MHD) is now a widely used life support system for patients with end-stage renal disease. Studies have shown that the number of patients requiring dialysis is estimated to be between 4,902,000 and 7,083,000 worldwide.³ Maintenance hemodialysis (MHD) sustains 89.4% of China's dialysis population,⁴ yet imposes severe

physical, psychological, and financial burdens due to high costs and complications. Without effective disease management, 5-year survival rates for ESKD patients remain critically low (41% globally; 60% in Japan).⁵ Diet therapy is an important part of disease management in patients with end-stage renal disease. Poor diet therapy can further exacerbate the negative psychological and physical effects on patients, which in turn increases the cost and burden of healthcare for the state.⁶ The World Health Organization (WHO) defines youth as ages 18–44, a demographic that serves as both the primary economic providers for families and key drivers of social development, warranting targeted attention. In terms of duration of illness, young patients will be on dialysis for a longer period of time, and prolonged dialysis will increase the risk of associated complications, such as heart failure and malnutrition.

Diet therapy of dialysis patients is closely related to post-dialysis complications, and unhealthy diet therapy can lead to food overload, electrolyte disturbances, hypertension, and malnutrition.^{7,8} In Spain, about 50% of MHD patients have unhealthy diet therapy skills.⁹ The dietary situation was even worse in Turkish patients, with up to 66.7% having varying degrees of dietary noncompliance behavior.¹⁰ To some extent, serum trace element or mineral concentrations in MHD patients can reflect the level of diet therapy. The prevalence of hyperphosphatemia in the UK is 35.9%,¹¹ and the blood phosphorus compliance rate in China is only 60%.¹² Complications resulting from unhealthy diet therapy both increase patient suffering and have a serious negative impact on dialysis outcomes, long-term survival and quality of life.⁶

Young people are in the critical period of school and work, and the occurrence of ESKD and the long-term needs of MHD can have a strong negative impact on the career development, family responsibilities and reproductive fertility of young patients, which may directly interrupt the balance of social adjustment. Statistically, 82.5% of MHD patients are in the low to moderate level of social support and have a moderate to high level of social alienation.^{13,14} Young MHD patients need clinical attention to help alleviate their negative psychological state and promote reintegration into society.¹⁵ Psychosocial factors play an important role in the diet therapy of patients. Over a longer survival period, the young population can develop negative emotions such as anxiety, depression, fear, and self-loathing due to excessive worries about dietary control and social life.¹⁶ In the United States, about 20% of people with chronic kidney disease (CKD) suffer from depression.¹⁷ Young MHD patients need diet therapy and re-adaptation to social life. Failure to perform good diet therapy and social adjustment can cause serious complications, accelerate disease deterioration, and seriously affect patients' physical and mental health. Therefore, it is important that we take into account the individual perceptions of young people with MHD, including the barriers they encounter, their feelings, and their choices of management when developing diet therapy and social support programs for young people with MHD.

Some studies have found that the complications associated with ESKD patients can be improved by dietary treatment (eg, application of dietary fiber or polyunsaturated fatty acid, etc).^{18,19} Application of healthy eating patterns can reduce mortality and ESKD in CKD patients.²⁰ Therefore, dietary therapy is crucial for symptom management in ESKD patients. However, current diet therapy lack targeted interventions for ESKD patients of different age groups, especially young ESKD patients. In the study survey, it was mentioned that about half (47%) of the registered HD patients were in an independent but unemployed status, and it was concluded that the better recovery and employment status of HD patients was associated with being young and male.²¹ However, many current studies have focused on the analysis of complications and causes of death, and have lacked attention to the social adaptation of this group of patients.

One study investigated the experience of barriers to dietary adherence and strategies for hemodialysis/peritoneal dialysis patients, providing a referable basis for open communication and nutritional education on dietary adherence.²² Several studies have focused on the influence of Chinese culture on the eating habits of people with MHD, with recommendations for culturally sensitive dietary education.²³ For young people with MHD, there is a unique experience of disease awareness and social activity as they experience the long-term fine-tuned dietary control and imbalanced social adjustment caused by the disease. Their perceptions of diet therapy and social adjustment are idiosyncratic and their details deserve attention. Most previous qualitative studies have focused on dietary adherence, dietary behaviors, and quality of life in the elderly population or in the entire age range population,^{24–26} and lacked the perceptions and experiences of diet therapy and social adjustment in young MHD patients. Therefore, there is a need to conduct relevant qualitative studies for young MHD patients.

Knowledge-Attitude-Practice (KAP) theory was proposed by Harvard professor Mayo and others, developed by Gochman in his editorship of *Health Behavior*, and successfully applied to health behavior change. Information-

Knowledge-Attitude-Practice (IKAP) theory is a new health-related behavior change theory based on KAP theory. It includes information, knowledge, attitude and practice and focuses on communication and interaction between caregivers, families, patients and the community.²⁷ This study utilized the IKAP theory to develop an interview outline that could provide a broad and in-depth understanding of patients' feelings and needs in terms of gathering information, acquiring knowledge, forming attitudes, and changing behavior. The development of an interview outline using IKAP theory allows for a wide range of insights into the patient's feelings and needs in terms of gathering information, acquiring knowledge, forming attitudes, and changing behaviors. This provides a framework for integrating and analyzing facilitators and impediments to diet therapy and social adjustment in young MHD patients. The aim of this study was to explore young hemodialysis patients' perceptions and experiences of diet therapy and social adjustment based on IKAP theory, and to provide a reference for healthcare professionals to develop targeted intervention strategies.

Methods

Participant Selection

We used purposive sampling to select 19 young patients who underwent hemodialysis at a tertiary hospital in Henan Province from June to August 2024 for semi-structured interviews, and all interviews were conducted individually. Participants were required to meet the following criteria: 1) aged 18–44 years; 2) meets diagnostic criteria for end-stage renal disease; 3) receiving hemodialysis treatment for at least 3 months; 4) able to communicate in Mandarin; 5) informed consent. We excluded patients with cognitive impairment, hearing impairment, psychiatric disorders.

Research Design

This study follows the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines for transparency and replicability. A descriptive phenomenological research methodology was used with open-ended semi-structured interviews in the form of face-to-face interviews to encourage participants to describe their experiences of diet management and social adjustment. The research team members were all registered nurses who had participated in training related to qualitative research. Prior to the interviews, team members read the patients' case files in detail to understand each patient's situation. We conducted a literature search and group discussion. The aim was to develop an interview outline based on the IKAP theory in terms of information, knowledge, beliefs, and behaviors related to patients' diet therapy and social adjustment. Pre-interviews were conducted with two patients, and the interview outline was modified and refined through group discussion based on the interview format and participants' responses. The finalized interview outline is shown in [Table 1](#).

Table 1 Semi-Structured Interview Schedule

Domain	Interview Question
Knowledge Information	Do you know what diets need to be controlled and why these foods should be restricted? How did you gain knowledge about dietary control? What specific difficulties have hindered your access to or understanding of dietary control information? Please describe specifically.
Attitude	How has your understanding of dietary management and hemodialysis protocols affected your studies, work, and daily life? How do you understand diet control? What do you think are the main factors that influence you to control your diet?
Practice	What do you think are the main factors of diet control and hemodialysis treatment that affect your work and life? What would you like the health care provider to do to help you? How did you manage your diet ? How do you deal with obstacles when it comes to dietary control? How are you coping with the effects of dietary control and hemodialysis treatment?

Note: The Domain section of the Semi-structured interview schedule is based on the Information-Knowledge-Attitude-Practice (IKAP) framework.

Data Collection

The location where we conducted the face-to-face interviews was the interview room of the hospital's hemodialysis center. The interview room was separate and quiet, and only the interviewer and participant were present during the interview. We made recordings with the consent of the participants. All interview questions were phrased in Mandarin and interviews were limited to 20~60 minutes. We briefly recorded the patient's conversation, tone of voice, and facial expressions during the interview in order to clarify the meaning to the patient in a timely manner during the process, and to help obtain more detailed information about the patient's interview when analyzing the data. Interview data collection and data analysis were conducted simultaneously, with data saturation used to determine sample size.

One researcher had more than 10 years of professional nursing experience in maintenance hemodialysis. She has provided maintenance hemodialysis care to participants for 12 to 96 months and has established good trust and understanding with participants. The interviewer for this study was a postdoctoral psychologist. Prior to the formal interviews, this researcher assisted the interviewer in conducting an initial interview with each participant to increase the foundation of trust for the formal interviews. This helped the participants to learn more about their life situation and to explore and express their true inner feelings during the formal interview. The formal interview, the second interview, was completed independently by the interviewer.

Data Analysis

Our analysis was grounded in the IKAP theory's four core elements (Information, Knowledge, Attitude, Practice) as an a priori analytical structure. Following Colaizzi's seven-step phenomenological analysis,²⁸ we systematically extracted and synthesized raw textual data to identify key themes. When emergent themes fell outside the conventional IKAP domains, research team consensus determined whether to expand the coding framework through deliberative discussion. The interview data were examined according to the steps outlined in [Box 1](#). The audio recordings of the interviews were transcribed into written manuscripts within 24 hours, then independently reviewed and cross-checked. The manuscripts were subsequently returned to the participants for verification and corrections. After receiving the corrected manuscripts, the transcriptions were carefully read multiple times to familiarize the researchers with the content. Each recurring meaningful text unit was manually coded. The identified meaningful units were then analyzed and discussed, leading to the refinement of preliminary themes. For example, the statement "Patients search for dietary knowledge through the Internet" was coded as "Search for dietary information on the Internet". Similar preliminary themes were grouped and condensed into subthemes. For instance, the code "Patients search for dietary information through the Internet" was categorized under the subtheme "Active access to information". Themes were then established and grouped under broader categories. For example, the theme "Access to dietary information" included subthemes such as "Active access" and "Passive access", which were further represented by codes like "Internet access to dietary information" or "Asking healthcare professionals". In cases where disagreements arose regarding the categorization of codes, the original manuscript was revisited, and consensus was reached through discussion and clarification of the meaning and interpretation of

Box 1 Colaizzi qualitative analysis steps

- Step 1: Each patient was coded to fully familiarize and understand all the information provided by the participant through careful and repeated readings
- Step 2: Analyze information in detail, identifying and extracting important and meaningful statements that recur and are relevant to the research question
- Step 3: Coding recurring ideas to distill units of meaning
- Step 4: Pooling the coded ideas, the theme takes shape through team discussions to find meaningful common concepts.
- Step 5: Excerpts from participants' original statements provide a detailed description of the topic
- Step 6: Similar prototypes of themes and their descriptions are put together for repeated comparison and discussion to identify and extract similar ideas and construct themes
- Step 7: The parsed data results are fed back to the participants for validation

the codes. Additionally, regular team meetings were held to discuss coding, subthemes, and the definitions of themes to ensure consistency and reliability of the findings.

Quality Control

Ensure the trustworthiness of qualitative research. (1) Trustworthiness: researchers analyzed interview transcripts and audio files, held team meetings to sort out and analyze themes, and provided feedback to participants on the data to test the accuracy of the interview texts. (2) Transferability: interviewers were intensively trained to verify interview content and outlines after pre-interviews or first interviews. Provide detailed information about the researcher, participants, sampling methods, data collection and analysis for comparison. (3) Dependability: Through group discussions, we examined whether the categories developed by the coding could be used to analyze other passages in the interview data and to assess and review the research protocol. (4) Confirmability: the use of triangulation and, in the event of disagreement, the researcher's return to the original data for ongoing comparison and reflection, to reduce the impact of the researcher's biases and limitations and to recognize in a timely manner the flaws and potential impact of the research methodology.

To ensure the quality of the study, all members of this research team were practicing nurses, and two of the researchers were associate researchers. Except for one researcher who was a charge nurse, all the researchers had a master's degree or higher or an associate chief nurse or higher title, and all of them specialized in nursing. The researcher completed the qualitative study under the supervision of the two associate researchers. Since she had no relevant qualitative research experience prior to her participation in this study, all her work in this study was done in collaboration with others and under strict quality control. Other researchers had participated in systematic training related to qualitative research during their master's or doctoral studies. Some researchers had been involved in qualitative research and had published academic papers on the subject. Members of the research team were familiar with each other and usually used online meetings and WeChat for group discussions to maintain regular contact and feedback, and the software that provided technical support for the online meetings was "Zhumu Meeting". (<https://zhumu.com/>)

Ethical Approval

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki. This study was approved by the Third People's Hospital of Henan Province Institutional Review Board on May 29, 2024 (Approval No. 2024-SZSYKY-021). The researcher provided participants with a detailed description of the purpose and methods of this study. The researcher details the participant information protection component, including what will be disclosed and what will be non-public. All participants were fully informed of the study purposes and voluntarily provided written informed consent, including explicit permission for publication of anonymized data and direct quotes.

Results

Sociodemographic Data

Participants sampled for this study did not refuse to participate or withdraw. We ended up conducting a total of 19 semi-structured interviews. The participants were 13 males and 6 females, aged 25 to 43 years, duration of dialysis ranged from 1 to 13 years, 13 were in high school and above, and 7 had monthly incomes of more than ¥5,000 informed consent was obtained from the participants for both the interviews and the audio recordings, which were transcribed into textual transcripts within 24 hours after the interviews, and the demographic characteristics of the participants are shown in Table 2.

Themes

From the data analysis of the interview data, we summarized five themes: (1) diet therapy perceptions, (2) diet therapy behaviors, (3) access to dietary information, (4) family roles, and (5) challenges of social adjustment (Table 3).

Table 2 Demographic Characteristics of Participants (n=19)

Characteristics	Categories	M ± SD	n (%)
Age		35.42±5.45	
Sex	Male		13 (68.4)
	Female		6 (31.6)
Dialysis vintage (months)		74.26±49.72	
Education level	Junior high school		6 (31.6)
	High school		4 (21.1)
	College		6 (31.6)
	University		3 (15.8)
Monthly income	<2000		5 (26.3)
	2000~4999		7 (36.8)
	5000~9999		3 (15.8)
	≥10000		4 (21.1)
Living with family	Yes		15 (78.9)
	No		4 (21.1)

Table 3 Theme and Sub-Themes

Theme	Sub-themes
Diet therapy Perceptions	Lack of knowledge Imprudent attitude
Diet therapy behaviors	Vigilant Diet Anxiety about water Control of salt
Access to dietary information	Active acquisition Passive acquisition
Family Roles	Changes in dietary habits Support of information Reducing family involvement
Challenges of Social Adaptation	Barriers to work Socialization Pain Points Emotional distress Looking for a way out

Theme One: Diet Therapy Perceptions

Subtheme One: Lack of Knowledge

Patients often apply their life experiences with diet to the diet therapy of their disease, but these are often inapplicable or incorrect. In turn, they have their own dietary control bias and will focus on the diet therapy required for different complications based on routine blood tests, but this can result in some knowledge blindness.

N2: I don't know why I can't eat egg yolks, I just know that if I eat this, I have high cholesterol, that's how I understand it.

N8: I think the main thing is to just watch out for high potassium, the rest doesn't seem too serious. I also know less about high phosphorus and high calcium, anyway, I know what I often eat, control what I eat now and check.

Subtheme Two: Imprudent Attitude

After the disease, patients do not pay attention to their “health” status, believing that the disease does not bring serious adverse symptoms to the body and that the need for diet therapy is not urgent, and maintaining a dispensable attitude. They also believed that they were young and should eat as much as they wanted, and suggested that in the future, when the worsening of the disease would result in severe dietary restrictions, it would be more important to enjoy food now, otherwise it would be a loss in life.

N5: I just feel like I do not have any pain or symptoms, so I do not deliberately control my diet.

N10: It is supposed to be time to eat and drink. Anyway, it will be a loss if you can't eat or drink when your health is not good anymore.

Theme Two: Diet Therapy Behaviors

Subtheme One: Vigilant Diet

Following complications of kidney disease, such as hyperkalemia or hyperphosphatemia, patients typically develop heightened vigilance toward potentially problematic foods, leading to reduced or complete avoidance of subsequent intake. While such dietary restrictions may enhance the efficacy of nutritional management to some extent, they also predispose patients to neglect other essential dietary components.

N13: In the past, when I was on dialysis elsewhere, the potassium was relatively high, I felt so sore and weak that I could not stand up, and then I realized that the potassium was so high that it was prone to sudden cardiac death, so I was very careful, and I seldom ate fruits like bananas directly.

Subtheme Two: Anxiety About Water

Many patients believe that weight gain and water intake are very important for hemodialysis. They will severely limit their daily water intake. They will resort to alternative ways of quenching their thirst, such as: gargling liquids only, consuming tomatoes, etc., which puts them at risk of overprotection. The prolonged state of thirst can cause anxiety and distress, decrease patients' appetite, and increase the desire to drink and self-satisfaction.

N4: Drinking water is quite troublesome, I basically don't drink much water, I rinse my mouth from time to time when I am at home, and sometimes I am particularly thirsty, which makes me anxious and distressed.

N12: When I come home from my stall at night, I don't even want to eat, I just want to drink some water. When I see people drinking water, I feel very thirsty myself. It feels so good to have a sip of water, I have never had such a luxury.

Subtheme Three: Control of Salt

Some patients valued the control of salt and sodium intake, believing that excessive salt intake would exacerbate the state of thirst, weaken self-control over the amount of water consumed, and increase the pain of diet therapy. Most of them chose to limit salt and sodium intake by using weight-measuring aids in cooking. A few patients reported that they no longer put salt in their meals and relied only on complex spices for food flavoring.

N11: The very small weighing spoons bought online with a graduated scale that weighs the grams of salt.

N12: I don't put salt in my own cooking anymore, I just put some other seasonings, like Nande, and I don't put any salt in it at all.

Theme Three: Access to Dietary Information

Subtheme One: Active Acquisition

Most patients tend to use the Internet to acquire knowledge about diet therapy. They learn the scientific knowledge points of diet by querying browsers and searching public numbers. They consider this approach more convenient, but the

information tends to be fragmented, lacks accuracy, requires filtering and verification, and sometimes fails to provide the specific content they seek. In addition, they also indicated that they would take the initiative to ask doctors and nurses because healthcare professionals providing professional knowledge would make them feel more secure.

N9: Sometimes when I am not feeling well, I will check online to see what dietary problems I have, after all, the doctor can't be by my side at all times, and the information on the internet will be more detailed, but not comprehensive. I have also exchanged information in patient groups and then went to some public numbers.

N16: I have asked doctors, nurses and patients. I asked the attending doctors and nurses more often because they are more professional.

Subtheme Two: Passive Acquisition

Some of the patients, although they do use the Internet and the collective teaching of the department, stop only at receiving the knowledge given by the healthcare professionals, neither outputting nor giving feedback information. They said that the nurse's explanations were quite sufficient for use and there was no need to carry out the process on their own. However, the usual diet therapy of these patients was not satisfactory, and it is possible that the patients need to re-establish the right attitude in terms of information reception and understanding.

N1: The nurses would post some knowledge about diet therapy in the hospital's official WeChat public account (a subscription-based information platform), and then the WeChat group would also post some knowledge about it. During dialysis, the nurses will also explain some things so that it is better controlled.

N3: It is mainly the regular radio propaganda and collective education activities in the dialysis room, where the medical staff will give us some precautions for dialysis. In addition, I often play Jitterbug and occasionally brush the hospital's science tweets.

Theme Four: Family Roles

Subtheme One: Changes in Dietary Habits

As the patient's exposure to knowledge about diet therapy increased, family members would follow the patient's lead in reducing the intake of oil and salt in food, and gradually develop new eating habits by changing the way they cooked and eating out less in the belief that this would lead to a healthier body.

N2: Because of my illness, the overall salt intake of our family is now being reduced. My family used to be more concerned about taste, but now we are eating a little healthier, with less oil and salt in our diet. I used to pour the cooking oil directly, but now I buy a spray bottle to control the amount.

N15: My family generally follows my taste, which is as light as possible.

Subtheme Two: Support of Information

After some patients became ill, their family members chose to give protection and help to the patients, actively learn about the disease, and give support and supervision to the patients in the position of family members.

N11: My parents would ask me what my blood counts and dialysis volume were after I finished dialysis, and if they were higher, they would ask me: Did I drink too much water? Did I eat too many apples? And then supervise me to eat less.

N18: Because I was sick, when I first started dialysis, my loved ones kept buying all kinds of information to read, consulting and understanding the situation from doctors and nurses, and asking what should be done to help me.

Subtheme Three: Reducing Family Involvement

Some patients clearly realize the importance of diet therapy and take active steps. However, they think it will increase the burden on their families and will try to cut out the help brought by their families and face the troubles and difficulties in diet therapy by themselves. They stated, I do not want to tell my family about my condition, it will bring trouble to my

family, I am still young, I can deal with the problem by myself, it is convenient. Out of this thinking, patients chose to cook their own meals, get their own information about diet and treatment, and keep it confidential.

N4: I don't want my family to know all these things related to diet control and disease treatment, I don't want to worry my family. I need to eat lighter, and sometimes my family will cook with the wrong taste or poor control of the amount of salt, so I might as well do it myself, it's easier and better controlled.

N8: I haven't talked to them about dietary things, I just know what I can eat on my own, and they can eat whatever they want. If I come across something I can't eat, I'll eat less or even not eat it.

Theme Five: Challenges of Social Adjustment

Subtheme One: Barriers to Work

The need for patients to undergo hemodialysis several times a week causes them to be questioned about their work efficiency and competence, which results in the loss of formal jobs, either actively or passively. And they suffered obstacles in their repeated attempts to get employed again, leading to failure in social work entry. This caused them to develop a huge psychological gap, anxiety about their future career development, denial of their personal values, and insomnia.

N4: I no longer have my old job and now it's all temporary work. I've gone to interviews with several companies and because of my illness, even if I pass the interview, they won't hire me anymore. This makes me anxious, and I basically go to sleep at one or two o'clock at night now, and then wake up at four or five o'clock.

N7: I've looked for jobs almost 30 times and have been rejected about 20 times. It's not easy to find a job at all, it's hard to find one.

N13: I used to work as an interior designer and was able to go to work regularly. Lost my job when I got sick; now too many people are employed and there is no way a company is going to go and find someone who is sick to be an employee. Feeling like I've become an invalid and feel useless.

Subtheme Two: Socialization Pain Points

In China, wine has an important social function. Friends get-togethers, work needs, etc., usually use wine to enhance feelings and promote good interpersonal relationships and work atmosphere. Patients are not allowed to drink alcohol at get-togethers due to the need for diet therapy, which makes them more passive in socialization. They expressed embarrassment and boredom at get-togethers when they were the only ones who did not drink, and their friends and themselves cut back on get-togethers. And the loss of work reduces the patient's avenues of social contact. The loss of conversation with others exacerbates the social disconnect, leaving the patient in a degree of social isolation.

N5: They won't come to me, I'm sick, they are afraid to take responsibility. When we had dinner, others drank and chatted, but they wouldn't let you drink, it was meaningless to sit there, and then almost all of them didn't go.

N7: Sometimes they don't bring me to friends' dinners because they know I don't dare to drink water or alcohol. And they all have their own children and families, to struggle and work hard, we had no common topics before, and have been estranged.

N9: I used to go out to eat with my colleagues and friends. Now that I don't have a job, my coworkers' dinners have become rare, and my friends don't see each other much. I think it's good not to affect them. I don't want to cause trouble for my family and friends.

Subtheme Three: Emotional Distress

Some of the patients described their former life plans and life expectations, indicating that they felt pain, low self-esteem, depression, and inability to regain their enthusiasm for life for their unattainable life values, and these patients were not yet 40 years old.

Some patients believed that they were in their youth, but they could not manage their lives independently, could not create social value, and not only could not feed their families, but also needed to rely on their elderly family members (parents), which made them believe that they had brought a heavy burden to their families, and generated profound guilt and self-blame.

N4: I have no more plans or expectations for my life and work. Look at my age, I'm half buried in the ground.

N16: I feel that if I get sick at a young age, I can't create value, and psychologically I feel unequal. I feel that I have an inferiority complex when I compare myself to others.

N6: My parents are over 50 years old, and not only do I not create any value for them, but I also squeeze them. I feel sorry for them, and I feel that way, I'm sorry, I'm sorry.

Subtheme Four: Looking for a Way Out

Some patients had the courage to overcome their difficulties and were determined to make a difference. They reconcile with themselves, make new attempts, develop new careers, work hard to find a new balance between life and illness, stabilize their illness and psychological state, and discover the meaning of life. They bet on temporary, trendy or time-flexible jobs to stay in communication with society and life as much as possible, withdrawing themselves from the pain of their illness and increasing their satisfaction and happiness with life.

N8: That one posts a video on Shakeology and does a little internet history science.

N11: My job is a shopping mall manager. I applied for an adjustment to the evening shift so that I can have dialysis in the morning and go back to work in the afternoon so that I don't have to delay either way.

N13: I will temporarily help out at a friend's company and get involved in interior design. If I have a job, I can adjust my mood and I won't be thinking nonsense.

Discussion

It is well known that nutritional status is critical for MHD patients to alleviate systemic inflammation, muscle wasting, improve quality of life, and reduce the risk of death.^{29–31} And the control of diet and dialysis can limit patients' social abilities to some extent. A comprehensive understanding of patients' dietary and social life experiences is an important part of designing and implementing a proper nutritional and social support program. The young MHD patients in this study analyzed the links, pros and cons, and risks of diet therapy and social life according to their own circumstances. However, most of the patients felt that the prolonged diet management itself had already caused them great stress, and that the balance between diet and treatment had made it difficult for them, and that these stresses and difficulties had left the patients at a loss as to how to achieve a good social life.

This study found that some patients lacked disease-related knowledge and held misconceptions about diet therapy, including its rationale, consequences of poor management, and food preparation methods. The lack of knowledge about the disease caused patients to ignore the importance of diet therapy, develop a belittling mentality, and indulge in eating. Studies have shown that patients' positive attitudes toward eating increase their satisfaction with life.³² Lack of health education about the disease is a major cause of misjudgment and cavalier attitudes among patients. Systematic evaluations confirm that well-designed health education programs significantly enhance patients' disease knowledge and self-management behaviors.³³ Other studies have proposed that there are significant differences in nutritional knowledge among MHD patients with different literacy levels, with the lower the literacy level, the more inadequate the knowledge.³⁴ This may be related to the lack of initiative, lack of awareness of the importance of learning about nutrition, and weak comprehension of patients with lower literacy levels. Some younger patients in this study demonstrated passive knowledge acquisition, equating exposure to information with mastery. This overconfidence, coupled with insufficient understanding, contributed to dietary mismanagement. In contrast, others proactively sought nutrition guidance through digital platforms or consultations with healthcare professionals. This is different from previous

studies.²³ They had fewer questions about diet therapy. This may be related to the fact that patients are younger, have higher education levels, and are more likely to access and accept new online media. This further suggests the importance of enhancing patients' health literacy and innovative knowledge acquisition channels. The educational needs of young hemodialysis patients were analyzed by categorizing them according to health knowledge levels and residual renal function, with key influencing factors identified. Integrating intelligent technologies (eg, microfilms, short videos, and AI-assisted platforms) into personalized education models may enhance patients' health literacy.

Patients in this study demonstrated heightened dietary vigilance regarding potassium and phosphorus due to prior experiences with hyperkalemia and hyperphosphatemia. While this promoted strict behavioral control, excessive focus on these elements risked neglecting other nutritional requirements (eg, protein-energy malnutrition, anemia). Such hypervigilance—potentially linked to reduced social engagement and information gaps—warrants clinical attention.³⁵ MHD patients in this study consistently emphasized salt and water restrictions when discussing dietary modifications, reflecting their prioritization of these aspects in disease management. They recalled their own experiences and experiences with salt and water restrictions and felt that the water controls were too stressful for them. In fact, salt control is closely related to water restriction.³⁶ Thirst affects 30.9–95% of MHD patients, with salt taste perception being a significant contributing factor.^{37,38} Excessive fluid intake due to thirst may lead to volume overload, increasing risks of acute pulmonary edema and congestive heart failure while significantly compromising quality of life.³⁹ Dietary sodium restriction effectively reduces thirst and subsequent fluid intake, leading patients to adopt low-salt diets and fluid restriction. However, it is important to maintain a balance and accurately measure the amount of water intake that is acceptable for the treatment of the disease and to avoid over-restriction.

In this study, the paradoxical experience of being thirsty and wanting to drink, but not being able to drink large amounts of water due to over-control of water intake caused anxiety and distress to the patients. The lack of knowledge about diet therapy and neglect of residual renal function may have contributed to this situation. Patients were unable to determine the appropriate amount of water to drink based on their residual renal function, combined with nutritional knowledge, and blindly reduced or even did not drink water and persisted in this habit for a long time.⁴⁰ This exacerbates disease progression and increases psychological distress. Targeting water-sodium imbalance through advanced assessment tools⁴¹ and optimized residual renal function utilization may improve fluid/sodium regulation, thereby alleviating disease burden in MHD patients.

The communal meal system has been a tradition in Chinese family dining, with other members of the family consciously assuming the role of caregiver when a family member becomes ill.⁴² Therefore, in daily life, most families will cooperate with the need for diet therapy of MHD patients to change their dietary habits and provide support for a favorable dietary environment. Studies have shown that positive family support increases motivation, improves health literacy, and has a beneficial impact on the preventive management of chronic diseases.⁴³ Encouragement and assistance from family members in terms of dietary information and daily supervision will help patients to pass through the fluctuating period of the disease more smoothly and to better establish and adapt to a new life pattern. Some of the young patients in the study were supported and assisted by their family members to maintain a good living condition. However, some of the young patients expressed that they did not want their families to be involved in the management and control of the disease. They believed that they were still young and capable of taking care of themselves, and preferred to keep their families in the same state as before. They manage themselves by cooking their own meals and getting information themselves, and are at a relatively good level of management. The study suggests that good self-efficacy is particularly important for dietary interventions for younger MHD patients and that the effectiveness of their dietary interventions is related to the state of their self-efficacy.⁴⁴ The higher the self-management efficacy, the more effective the dietary intervention. Therefore, although family support is crucial, it is also necessary to take into account that patients are young people with a certain degree of self-management ability. A study implemented a peer support combined with family participatory dietary intervention in 104 hemodialysis patients with chronic renal failure and found it to be effective in improving nutritional levels and reducing adverse psychological states.⁴⁵ A randomized controlled study effectively improved patients' nutritional status and quality of life by implementing individualized dietary adjustments under informational nutritional screening for MHD patients.⁴⁶ When carrying out the intervention, it should be tailored to different patients' situations, actively explore their self-management potential, and with the appropriate level of family

support, the effect of diet therapy can be better utilized to promote the effective control of the disease. When carrying out the intervention, the self-efficacy level of the patients should be paid attention to and assessed, and the cognitive and psychological status of the patients should be fully considered. By building an intelligent decision-making platform that can make dynamic decision-making suggestions based on the patient's stage-by-stage intervention results, and developing game applets with management encouragement mechanisms, we can assist patients in tapping their self-management potential, better exerting the effects of diet therapy, and promoting the effective control of the disease.

As one of the countries with the oldest brewing technology in the world, China's drinking culture is an important part of Chinese culture. And while drinking plays an important role in the daily lives of Chinese people, the Chinese drinking culture encourages drinking with a social component as opposed to drinking alone. Drinking alcoholic beverages contributes to positive interactions between people and is an important way to maintain relationships and develop a career.⁴⁷ Most of the male patients in this study were clearly disadvantaged in social gatherings among friends and colleagues after being restricted from drinking alcohol. They are unable to integrate into the meal atmosphere, develop significant social withdrawal behavior, and then gradually lose their normal social life. Another factor that also affects the social life of the patients is the loss of their jobs. Which cut off an important channel of their daily interaction with the society. They were unable to expand new coworker relationships and had significantly fewer opportunities to meet and interact with their old work relationships, further exacerbating the patients' lack of social life.

In addition, the interruption of their careers created another serious problem, as the young patients felt that they were unable to realize the value of their lives, that they were causing ongoing harm to their families, and that they were a burden on their families' lives and finances. The sense of guilt brought about by this psychological fallout makes them feel anxious or depressed, generates self-avoidance behaviors, or even loses expectation and motivation for life and self-abandonment, which seriously affects their quality of life. This may be related to self-perceived burden. Patients with self-perceived burden spawn negative psychology and lower self-perception because of the continued growth of dependence on the caregiver, and it is the source of the patient's guilt about the predicament in which the caregiver finds himself or herself.⁴⁸ Adaptive emotion regulation strategies are a variety of targeted emotional intervention strategies to increase social interaction situations to enhance an individual's positive emotions and reduce negative emotions such as loneliness. It fully engages the patient's subjective initiative and active participation in treatment decision-making, which in turn increases resilience to disease transitions and strengthens patient motivation and confidence.⁴⁹ A study of 60 patients with end-stage renal disease who underwent cognitive therapy for 5 weeks and were followed up for 4 weeks found that cognitive therapy significantly reduced participants' negative emotions and resulted in positive changes in patients' positive emotions and sense of social well-being.⁵⁰ Therefore, a proactive attitude from the outset and effective emotional regulation and cognitive restructuring are crucial for young patients. Nocturnal prolonged hemodialysis can provide effective dialysis at night without undue disruption of daily life. Studies have shown that nocturnal dialysis improves symptoms and improves quality of life through free time during the day.⁵¹ Its development may bring new entry points for young patients' social adaptation. In addition, the need for social and family support cannot be ignored. Evidence-based interventions should be implemented to address the psychosocial challenges of hemodialysis patients, including: (1) optimizing public health education initiatives, and (2) establishing corporate incentive policies for creating patient-accessible employment opportunities. These measures aim to enhance societal and familial understanding of hemodialysis, alleviate stigma-related psychological burdens. Eventually, patients can establish a good dietary management pattern and better adapt to social life.

There are some limitations of our study, the respondents of this study were limited to one hospital and the information obtained was more limited, a multi-center study could be conducted in the future to increase the comprehensiveness of the information. The results of the study may be at risk of recall bias, eg, patients may have vague memories of disease control details.

Conclusion

In conclusion, young people with MHD are aware of their need for diet therapy and social re-adaption. However, they suffer obstacles to diet therapy and social re-adaption and are unable to change due to lack of knowledge, insufficient social support, self-perceived burden, and other influences from themselves or the outside world. We believe that

innovating knowledge dissemination channels, optimizing dietary knowledge content, exploring nocturnal dialysis modalities, guiding the use of adaptive emotion regulation strategies, and making full use of patient self-efficacy are important for dietary control and social life in young MHD patients. In addition, the level of support at the national and societal levels should be strengthened to help patients establish support networks and social connections, thus improving diet therapy and social adjustment in young MHD patients. Future longitudinal studies should be conducted to examine the dynamic changes in psychological characteristics among young maintenance hemodialysis (MHD) patients throughout long-term disease and life management, which would help identify optimal intervention timing and pathways. Furthermore, innovative intervention strategies should be developed to improve dietary compliance in this population, with particular consideration given to the unique characteristics and needs of young patients through more intelligent and convenient approaches.

Disclosure

The authors declare no competing financial interests or personal relationships that could have influenced the work reported in this paper.

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