



Disease Experience of Maintenance Hemodialysis Patients: A Qualitative Study

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Abstract: Objective: To explore the diseases, psychological feelings, and treatment cognition of blood patients using qualitative methods. Method: Colaizzi phenomenological analysis is used to analyze data and extract themes. Results: The disease experience of maintenance hemodialysis patients can be summarized into four themes: acute medical and rescue events, early neglect of chronic diseases, economic considerations and resource scarcity, and regret and reflection on medical decisions. Conclusion: Patients face many challenges during the treatment process, and personalized services should be implemented to improve their quality of life and treatment outcomes.

Keywords: hemodialysis; experience; qualitative research

1. Introduction

Maintenance hemodialysis (MHD) is a crucial treatment method used to address the ultimate stage of renal failure in chronic kidney disease [1]. As the number of MHD patients increases, there are challenges in improving their quality of life and clinical care. Previous studies have mainly focused on the physiological and clinical aspects of MHD patients, but exploration of their disease experiences is still relatively limited [2]. Maintenance hemodialysis is not only a medical treatment, but also an important component of patient life [3]. This study aims to explore the disease experience of maintenance hemodialysis patients through qualitative research methods. Having a deep understanding of the patient's experience, challenges, and needs is of great significance for optimizing clinical care and improving quality of life.

2. Object and Method

2.1 Research subjects

The study used purposive sampling method to include stable hemodialysis patients at a tertiary hospital in Yunnan, aged ≥ 18 years, with normal communication, and excluding those with unclear consciousness and severe organic diseases. The sample size is 32, with 14 males and 18 females, aged 36-76 years old, and has passed the ethical review (DFY20240122001).

2.2 Research Methods

2.2.1 Design interview outline

Based on literature review, develop an interview outline, and after pre interviews and expert feedback revisions, form a formal outline. Starting from "treatment experience", gradually understand the patient's physical condition and disease experience.

2.2.2 Data collection

The researcher is responsible for conducting one-on-one structured interviews and selecting a convenient and quiet environment. Follow the principle of not interrupting or inducing, gradually deepen understanding, and each time for no less than 20 minutes. Obtain informed consent form and record the entire process.

2.2.3 Data analysis

After converting the interview recording into text, code it as P1~P32 and import it into Nvivo 20 software. Using the Colaizzi phenomenological 7-step analysis method: transcriptional data, inductive viewpoints, encoding, aggregation, listing encoding, sublimation themes, feedback.

3. Results

3.1 Theme 1: Acute medical and rescue events

MHD patients are usually in a state of severe renal dysfunction, and their physical condition may fluctuate, leading to

worsening of the condition. P6: "I had an accident when I was just undergoing dialysis before. I missed an injection and had a headache, which made me feel like I couldn't bear it anymore." P12: "This time it was particularly serious, and it caused me to almost go into shock. I was hospitalized and saved my life." P20: "When I was seriously ill, I came here for treatment, and they fixed it for me. I needed to take that hormone medication, and I felt swollen and overweight to over 120 pounds." P23: "I had a lung infection and went to the ICU for 15 days, but I couldn't wake up after leaving the ICU, just like I was a lunatic."

3.2 Theme 2: Early neglect of chronic diseases

In the early stages of the disease, patients may experience symptoms such as fatigue, edema, or reduced urine output, but due to various reasons, patients may not be able to timely link these symptoms with kidney function problems or seek medical help. When the condition progresses to the stage where maintenance dialysis is required, it is possible to review these early symptoms and realize that they are actually signs of renal failure. P11: "At first, my blood pressure was not well controlled, and then I had proteinuria. I didn't pay attention at the time, and then my hand broke. I had been taking traditional Chinese medicine for a long time, and kidney disease was a kind of mute disease. When I found out later, it was already kidney disease, which became serious. At that time, we were busy with work and didn't know more about our condition, which may be fatal. P18:" The initial symptom was a bit of headache. When I had a headache, I had been in pain for several years. After drinking a little cold water, I felt a good pain, and then I took that headache powder. After taking a pack, I anesthetized myself and left it alone. "P26:" We used to provide education for our children, and if their bodies were not good, we could go get a few injections and get them back. "" I haven't taken this to heart, haven't I checked it."

3.3 Theme 3: Economic considerations and resource scarcity

The only condition for MHD patients to no longer undergo dialysis is to undergo kidney transplantation. Due to various reasons, such as the scarcity of donors and high surgical costs, most patients are unable to achieve this goal. P7: "My son said he wanted to borrow money to exchange his kidney, but I said, 'Don't think about it. I can't afford it, and I see that some people who have had their kidneys changed haven't lived for a few years. I think it's because dialysis can maintain it now, so let's keep going.' P11: 'I want to go get a kidney change, but it's too difficult for the kidney source. So I've been in line for a while, and I haven't been able to get it yet.' P16: 'I had a vascular stent surgery before, which cost me over 193000 yuan. This year, my dad had the stomach surgery, which cost him about 20000 yuan. My family's money has already been spent, and those who used to want to get a kidney change can't afford it now.'" However, there are also cases of renal failure after kidney replacement, which requires dialysis treatment. P26: "I had a kidney transplant before, but it didn't work out ten years later. I still came for dialysis."

3.4 Theme 4: Regret and Reflection on Medical Decisions

Patients who reflect on their medical decisions after illness may experience regret and disappointment in their decisions. P11: "I broke my hand before, and later I wanted to take Chinese medicine to recuperate, but I forgot to tell the doctor that my kidney was a bit bad, so he gave me a lot of Chinese medicine normally. Later, during a physical examination, I found that my kidney function was damaged, and I went for a kidney biopsy and found that the cause of kidney failure was drug damage." P31: "I went everywhere, and the money was wasted, but it was still useless. I spent more money than I did because I spent a lot of money in Beijing. If I had to choose again, I would definitely not go to Beijing for treatment. Instead, I wasted the money, which could replace my kidney."

4. Discussion

4.1 Dual pressure of body and mind

Hemodialysis patients often experience fluctuations in physical function, increased discomfort and risk of deterioration, and even life-threatening conditions due to factors such as electrolyte imbalance, fluid imbalance, hypotension, and infection caused by dialysis [5-7]. Dialysis itself may bring pain, and patients need to deal with the impact of the disease on their lives and future concerns, increasing psychological pressure[8]. It is recommended to undergo regular health checks, monitor indicators such as electrolytes, blood pressure, and fluid balance, adjust diet, control water and salt intake, report abnormal symptoms in a timely manner, and adjust treatment plans.

4.2 Enhancing public health awareness

Dialysis patients often face issues related to renal failure due to early neglect of chronic diseases [9]. Therefore, it is recommended to start from multiple aspects: enhancing public health awareness, strengthening awareness and prevention of chronic diseases, and promoting healthy lifestyles[10]. Enhancing awareness of chronic diseases, promoting healthy

lifestyles, regular health checks, early diagnosis and treatment, strengthening health education, establishing a community medical service system, and reducing serious complications such as kidney failure.

4.3 Rational decision-making

Chronic kidney disease develops slowly and is asymptomatic in the early stages[11], requiring long-term management of blood pressure and blood sugar. Treatment can delay progression, but late stages may be irreversible[12]. Patients should fully understand their condition and treatment options, participate in decision-making, consider risks, costs, and quality of life. At the same time, one should receive psychological support to cope with anxiety and stress.

5. Summary

This article investigates the disease experiences of maintenance hemodialysis patients. Discoveries include challenges such as acute medical events, early illness neglect, economic pressure, and lack of medical resources. The results highlighted the importance of personalized care to improve treatment outcomes and enhance quality of life.

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