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Original article

The psychological trajectory from diagnosis to approaching end of life in patients undergoing hemodialysis in China: A qualitative study



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ABSTRACT

Background: In China, the number of patients diagnosed with end-stage renal disease has increased rapidly in recent years. Patients undergoing dialysis treatment often experience psychosocial challenges, such as death anxiety, which may potentially cause patients to withdraw from treatment. Nephrology nurses and other practitioners who provide direct care to patients undergoing hemodialysis must understand how these challenges are perceived by patients and affect their daily lives.

Aim: This article investigated the psychological trajectory and life experiences of hemodialysis patients to provide complementary guidance for nurses and healthcare practitioners.

Method: This study utilized a qualitative descriptive phenomenological design. Data were collected by conducting semistructured interviews and analyzed by content analysis. Data were collected through in-depth interviews from May to December 2014. The questions were designed to reveal the life experiences and perspectives of hemodialysis patients. Participants were selected by convenience sampling approach and recruited from outpatients receiving treatment in a blood-purification center in Jiangsu Province, China.

Results: Twenty-three participants were recruited. Three stages were extracted from the interview data: (1) afraid stage, (2) adapted stage, and (3) depression stage. Accordingly, three corresponding stages of physiological status were identified: (1) induced stage, (2) stable stage, and (3) severe complications or approaching-end-of-life stage.

Conclusions: Patients undergoing dialysis exhibited differing psychological statuses at different physical stages. Thus, nurses must assess the psychophysiological symptoms of patients and design individual care plans for each stage. Future studies should focus on developing stage-specific nursing-care protocols.

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1. Introduction

A nationwide survey conducted in China in 2014 revealed that 2 million patients had been diagnosed with end-stage renal disease, of which 270,000 were undergoing hemodialysis. Patients undergoing dialysis manifest a high incidence of symptoms and suffer from an impaired quality of life [1,2]. Commonly described symptoms of dialysis include lethargy, muscle cramps, pain, loss of appetite, pruritus, sleep disturbances, anxiety, and dizziness [3]. Faced with a chronic illness and economic pressure, patients may

develop psychophysiological disorders. While undergoing treatment, dialysis patients are often confronted with psychosocial challenges, and studies show that 67.5% of such patients suffer from depression [4]. These challenges may lead to death anxiety, which could ultimately cause a patient to withdraw from treatment [5]. Thus, nurses in dialysis centers must evaluate the psychosocial condition of dialysis patients to improve the quality of their care [6]. This study investigated the psychological trajectory of dialysis patients.

1.1. Background

Several studies have used qualitative methods to gain insight into the experiences of dialysis patients. These studies have highlighted that dialysis treatment presents many challenges. I-Chen Yu and Yun-Fang Tsai [7] described the experiences of patients in

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Taiwan upon diabetes diagnosis to hemodialysis; these patients reported feelings of fear to face the process and outcomes of dialysis. Hagren et al. [8] elucidated that hemodialysis patients struggle with having restricted lives and having to depend on caregivers. These works clarify the psychological status of patients during one stage of the disease but fail to reveal the course of their psychological trajectory. Therefore, using a qualitative descriptive phenomenological design, this study examined the perceptions of hemodialysis patients at different stages to provide guidance for nurses and other healthcare practitioners who provide direct care to such patients.

1.2. Aim of the study

This study aims to gain insight into the psychological trajectory and experiences of hemodialysis patients to provide guidance for nurses.

2. Materials and methods

2.1. Design

The study utilized a qualitative descriptive phenomenological design, and data were collected by conducting semistructured interviews. Data were analyzed using content analysis [9].

2.1.1. Participants

Participants were selected by convenience sampling approach and recruited from outpatients receiving treatment at a blood purification center in Jiangsu Province, China. The eligibility criteria were as follows: (1) has undergone hemodialysis for at least six months; (2) aged above 18 years; (3) alert and oriented; and (4) willing to participate in an interview. The exclusion criteria were as follows: (1) mental health issues; (2) loss of cognitive ability; and (3) disturbance of speech.

2.1.2. Data collection

Data were collected by conducting in-depth interviews, which were designed to reveal a detailed assessment of the life experiences and perspectives of hemodialysis patients. Data were collected from May to December 2014. Semistructured and face-to-face interviews lasting 45–60 min were conducted by the first author at the bedside of the patients during hemodialysis. Data collection was completed once thematic saturation was reached and new themes did not emerge from subsequent interviews [10]. The thematic and exploratory interview questions were as follows: (1) In your opinion, what are the causes of your nephropathy? (2) Describe how you and your family reacted when the physician said that you had to undergo hemodialysis; (3) Have you experienced any changes in psychological status or life experiences since you began initial hemodialysis? (4) Describe how you faced hemodialysis and enumerate any coping strategies that you have used; and (5) Discuss your perceptions of your family members and the medical staff.

2.1.3. Ethical considerations

This study was approved by the ethics committee of the hospital. The dialysis center granted permissions for conducting the study. Patients who met the inclusion criteria were invited to participate and were further introduced to the purposes and procedures of the study. Participants wary of their privacy and confidentiality were assured that the results will not indicate their identities in any form. Participants were guaranteed that they could withdraw without penalty from the interview at any time and for any reason.

2.1.4. Data analysis

The interviews were recorded by tape, transcribed verbatim, and then analyzed using content analysis [10,11]. The researchers read the transcriptions to gain an overall sense of each interview and identify each participant's experiences. The texts were divided into meaning units, which were then merged as thematic units. Using continuous comparison and analysis, the researchers identified connections between the meaning and thematic units. The themes were then integrated into a structure depicting the participants' experiences [12].

2.1.5. Rigor

The accuracy of a qualitative research project depends on four aspects of trustworthiness: credibility, transferability, dependability, and confirmability. Credibility was satisfied by applying purposive sampling, prolonged engagement in the field, peer checking, and audit trails. Prolonged engagement during analysis builds trust from the participants, thereby improving credibility. The first researcher ensured authenticity by documenting memoranda and reflexive journals regarding the researchers' decision trail.

3. Findings

Twenty-three participants were recruited (Table 1). Participants described their psychological status and life experiences after being diagnosed. The interview data revealed three stages pertaining to the patients' psychological trajectory throughout the duration of dialysis. These stages were as follows: (1) afraid stage; (2) adapted stage; and (3) depression stage. Accordingly, three corresponding stages of physiological status were identified: (1) induced stage; (2) stable stage; and (3) severe complications or approaching-end-of-life stage.

3.1. Afraid stage

Upon learning from their physicians that renal failure had occurred, the patients felt very shocked and believed that they were unprepared to undergo hemodialysis. The patients explored alternative treatments from different sources to delay dialysis. When they commenced with dialysis, they felt afraid and worried about their future. Family support was very important during this stage.

3.1.1. Shock and denying the disease

At this stage, participants were in denial of their disease and were attempting to find out why they were suffering from it. They explored alternative treatments from different sources that might delay hemodialysis treatment. Participants felt scared and were unwilling to undergo dialysis, causing their uremic and somatic symptoms to worsen.

"When the doctor said that my kidney had failed and that I had to undergo dialysis, I felt shocked. I could not believe it. I did not know what dialysis was and did not want to undergo such treatment. My family began searching for alternative treatments from different sources, such as the Internet or other people. Eventually, our finances started to run out, and my disease was worsening. I am grateful to my family. They've always supported me." (Participant 1)

"I never found out the cause of the disease. When someone told me of a treatment regimen, I would try it and take traditional Chinese medicine." (Participant 22)

Table 1
Characteristics of patients.

Number	Gender	Age (Years)	Dialysis time (Years)	Chronic dialysis complication	Education level ^a	Initial disease	History of peritoneal dialysis
P1	Female	45	3	Hypertension	Primary school	Glomerulonephritis	No
P2	Female	52	2	Hypertension	Middle school	Glomerulonephritis	No
P3	Male	52	2	Hypertension	High school	Glomerulonephritis	Yes
P4	Male	34	5	No	Middle school	Glomerulonephritis	No
P5	Female	43	2	No	University	Polycystic kidney	No
P6	Male	34	2	Hypertension	University	Glomerulonephritis	No
P7	Male	47	6	No	Primary school	Glomerulonephritis	No
P8	Female	43	3	Renal anemia	Middle school	Glomerulonephritis	No
P9	Female	29	5	No	Middle school	Glomerulonephritis	No
P10	Male	62	3	Hypertension	Primary school	Hypertension	No
P11	Male	54	9	Heart failure	High school	Hypertension	Yes
P12	Male	44	7	Hypertension	University	Diabetes mellitus	Yes
P13	Male	54	5	Heart failure	High school	Diabetes mellitus	No
P14	Male	32	4	Hypertension	Middle school	Glomerulonephritis	No
P15	Male	54	9	Hypertension	High school	Hypertension	Yes
P16	Male	67	7	Renal osteopathy	Primary school	Diabetes mellitus	Yes
P17	Male	57	6	Heart failure	Middle school	Hypertension	No
P18	Female	65	10	Heart failure	High school	Glomerulonephritis	Yes
P19	Female	30	7	Renal osteopathy	Middle school	Glomerulonephritis	Yes
P20	Male	32	5	Renal osteopathy	Middle school	Glomerulonephritis	No
P21	Male	63	9	Hypertension	Primary school	Hypertension	Yes
P22	Male	45	6	Renal osteopathy	High school	Glomerulonephritis	No
P23	Female	67	3	Hypertension	High school	Hypertension	No

^a Primary and middle school 1–8 years, high school 3 years, university 3–4 years.

3.1.2. Fear of dialysis

Hemodialysis patients exhibited anxiety and depression from fear of the pain of the puncture, errhysis from the arteriovenous fistula, and adverse reactions to dialysis. Such scenarios are particularly apparent for participants with no history of peritoneal dialysis or family nephropathy history. New dialysis patients sought advice from other patients who had already undergone dialysis for several years. Young patients tended to obtain information from the Internet.

“I had completely no knowledge about dialysis. During the first time that I underwent dialysis, I was scared and worried the entire time. The puncture of the arteriovenous fistula was very painful. I was terrified that I gave up dialysis, making me very anxious.” (Participant 8)

“My mother was undergoing hemodialysis, so I was familiar to it. I am also the type of person who searches for new information. When I underwent hemodialysis, I did not feel scared.” (Participant 5)

“I have previously underwent peritoneal dialysis, which was ineffective. I then proceeded with hemodialysis, which was effective. During hemodialysis, I would share my experiences with other patients and seek for their advice.” (Participant 3)

3.1.3. Worry about the future

Having two or three dialysis sessions in a week affected the daily routines of the participants, making them anxious and worried.

“During my first time of undergoing dialysis, I went to the dialysis center with my son. My wife had already passed, and my son was busy. I had to undergo dialysis three times a week. I had no clue how I would function in the future.” (Participant 10)

“I had a good job before I was diagnosed. Now, I can only perform simple tasks. I have a large family. My parents are over sixty years old, and my son was seven years old. I did not know how to tell them about the diagnosis.” (Participant 6)

3.1.4. Six-month duration of the afraid stage

After six months, the uremic and somatic symptoms of the participants were gradually relieved. They had gained additional knowledge on hemodialysis, which reduced their anxiety and depression.

“I was very shocked during my first hemodialysis session. However, my fear was lessened as my uremic and somatic symptoms were relieved and the dialysis frequency increased. This adjustment took six months.” (Participant 1, Participant 8)

3.2. Adapted stage

Participants underwent hemodialysis regularly and had adapted to the treatment after six months. They accepted that dialysis was now a part of their life. Hemodialysis not only changed their diet and lifestyle but also affected their psychological health. Patients frequently displayed hemodialysis-related stress, yet the majority of them did not practice any effective coping strategies. Several participants reported that family support helped to relieve the stress.

3.2.1. Compliance

A number of participants willingly complied with the treatment to avoid any life-threatening side effects. However, other participants, particularly those who were young or employed, demonstrated low treatment adherence.

“I was fine. I did not eat food with high phosphorus or potassium, and I drank little water.” (Participant 7)

“I was an optimistic person and underwent dialysis regularly in the evening so I could go to work during the daytime. I had high treatment compliance and stable physical condition. My health insurance covered the costs of dialysis, so I did not worry about the expenses. I just accepted the dialysis as a part of my life.” (Participant 9)

“I have always liked noodles. I experienced difficulty changing my dietary habits. Although I understood the danger, I had trouble with self-control. During gatherings with family or friends, I did not want to seem selfish and ask them to eat a bland meal because of my condition.” (Participant 4)

3.2.2. *Self-pity*

In general, participants were able to live and work normally. Nonetheless, the restrictions of dialysis and the changes in their appearance induced feelings of self-pity and depression, making them unwilling to communicate with others. They were anxious about their future. They became immersed in their dialysis schedules and routines, and their daily lives became monotonous.

“Whenever I returned home after undergoing hemodialysis, I felt worn out and weak. I could not attend any social events and perform my familial roles and responsibilities. I was a young man, so I had to do some simple work to support my family. Whenever I pondered about my disease, I became stressed and anxious of my future.” (Participant 4)

“My life differed from that of others. I felt terrified whenever someone asked about my arteriovenous fistula because I did not know how to answer. I was reluctant to communicate with my colleagues. I declined their invites to go out. I had a daughter. She gave me hope, and I had to live to see her go to college.” (Participant 5)

“I felt shackled. I enjoyed travelling, which I can no longer do. Dialysis three times a week has made travelling even short distances difficult. When my friend recounted her visit to the countryside on a holiday, I felt self-pity.” (Participant 9)

3.3. *Depression stage*

When nearing the end of life, hemodialysis patients developed severe comorbidities, such as renal osteopathy, heart failure, and pulmonary infection. The deterioration of their bodies was exerting an even greater influence on their lives because of their increased dependence and progressive losses. Patients suffered a high symptomatic burden and an impaired quality of life. Participants expressed feelings of depression. They worried about the uncertainties of their end of life and hoped and they could enjoy their remaining days.

3.3.1. *Losing interest in life*

Increased fatigue was revealed as one of the most distressing problems associated with dialysis. Over time, the recovery period from dialysis treatment lasted longer. In addition to dialysis treatments, patients had medical appointments, and nearly all of the participants were occasionally admitted to the hospital. The combination of these factors caused patients to lose interest in life and feel depressed.

“Before, I used to feel normal after undergoing dialysis. Now, however, I just feel tired and weak. I now need more time to recover. I no longer have the energy to do anything – talk, walk, or communicate. I have lost interest in everything. My life now just consists of dialysis and other medical treatments. I am in hospital almost all the time. I have no choice.” (Participant 18)

3.3.2. *Facing death*

As their illness progressed, patients felt that their free time had

been diminished and their life had passed them by. They believed that their future was already behind them, and they were reluctant to think ahead, as they could only see death in their future.

“I was frequently feverish, and I could not sleep at night. What else was there to expect? I no longer cared about anything. I was just waiting for death. I had no other option but to accept the situation. The doctors prevented me from smoking, but smoking made me feel better for a while. I just wanted the pain to be lessened.” (Participant 11)

“My heart was unwell, and the pain in my chest was excruciating that I could not sleep. I knew that having cancer was worse, as my condition was not as painful but was also incurable. I was waiting for my death and just enjoying the present as much I could.” (Participant 17)

“I frequently fainted, and the doctor did not know the reason. My family has accepted that I would die someday.” (Participant 13)

4. Discussion

On the basis of these results, the time described by dialysis patients are divided into three stages according to their physical status. These three physiological stages include the induced stage, the stable stage, and the severe complications or end of life stage. The induced stage begins from the first hemodialysis and lasts until the stable stage. At this stage, the patients gradually accept hemodialysis and learn about it. Then, at the stable stage, patients begin undergoing hemodialysis three times a week. At the end of life stage, patients begin experiencing severe complications, as the hemodialysis increase in frequency. At the different stages, patients presented different psychophysiological symptoms, which are described in this study as three psychological phases. At the afraid stage, although patients have accepted the physical effects of hemodialysis, complete psychological acceptance among patients still require additional time; this study suggests this duration lasts for six months. At the adapted stage, patients exhibit anxiety and depression when facing vascular access dysfunction and acute hemodialysis complications, such as low blood pressure and hyperkalemia. At the end stage, patients displaying severe complications become weak and are admitted to hospital. They know that death is imminent, and they express feelings of depression. In this study, the three psychological status stages correspond to the three physiological status stages.

The interview data revealed that when physicians made the diagnosis, patients felt fear and searched for alternative treatments from different sources to delay dialysis, causing their symptoms to worsen. These results are similar to those obtained in previous studies. Some patients sought alternative treatments, such as herbs, health supplements, or traditional Chinese medicines, from advertisements and advice from other patients [13]. They hoped that the alternative treatments would postpone the need for dialysis [7,13]. These findings may help nurses to understand the life experiences of dialysis patients. The timing of the intervention by nephrologists and the clinical care team is crucial in helping patients accept dialysis more quickly [14,15].

As the dialysis treatments increased in frequency, the participants' uremic and somatic symptoms were relieved, and their knowledge on dialysis was increased, lessening their feelings of fear. The gradually adapted to the fact that dialysis was now a part of their lives. At the same time, participants underwent physiological and psychosocial stressors, such as lifestyle changes, role

disturbances, dialysis frequency, withdrawal from social lives, uncertainty, hopelessness, and depression. These results were familiar to those elucidated by Al Nazly [16]. A number of the participants controlled their diet, demonstrating high treatment compliance; this practice was associated with certain personality traits and family support. However, other young patients ignored the pain of the disease and were completely dependent on dialysis. They believed that assuming a new lifestyle and maintaining self-control were difficult to accomplish while routinely having meals with family or friends, during which they were often encouraged to eat more. As shown, family or friends may influence patients negatively and positively. These results are similar to those observed by I-Chen Yu and Yun-Fang Tsai [7] and Kaba et al. [17]. These studies indicated that the prevalence of non-adherence among dialysis patients was 40%–67% for medication [18,19] and 49.5%–80.4% for diet and fluid restrictions [20–22]. These data suggest that poor adherence is a worldwide health problem with considerable medical, social, and economic consequences [23]. Several studies have suggested that God, family, and friends can help patients cope with daily dialysis-related stress and encourage treatment adherence [16,24,25]. Spouses, children, or relatives, play important roles in supporting dialysis patients and improving their health status [26]. Thus, nurses should motivate patients to apply both internal and external approaches to confront the challenges of undergoing dialysis. At the same time, nurses should facilitate bonding activities between patients and their family and friends, who may provide patients with the needed emotional support or even help them comply with treatment regimens.

Despite the developments in dialysis treatment, the annual mortality rates for patients undergoing hemodialysis have been estimated at 20%–25%. This high mortality is mainly due to severe comorbidities, such as diabetes and cardiovascular diseases. At the depression stage, patients in this study suffered from severe complications and knew that death is imminent. Similar results were presented by Lena et al. [27], who suggested that hemodialysis patients became severely ill near their end of life. Dialysis units are focused on handling advanced medical technology and maintaining life; as such, end of life or palliative care may be neglected or overlooked. Therefore, studies on end of life care for these patients should mainly focus on dialysis termination. Nurses should monitor changes in the patients' disease and provide palliative nursing whenever possible. Previous studies have suggested that incorporating the palliative care into the technology of dialysis units may improve the care being provided for hemodialysis patients approaching their end of life and their families.

5. Limitations

Participants were selected using a convenience sampling approach and recruited from outpatients receiving treatment at a blood purification center in Jiangsu Province, China. Their opinions might not be representative of all patients undergoing hemodialysis from other parts of China or a randomly chosen sample.

6. Conclusions

This study investigated the psychological trajectory of patients from the moment of dialysis diagnosis until they experience severe complications to gain insight into patient education and clinical practice. Dialysis patients presented differing psychological status at different physical stages. Thus, nurses should assess the psychophysiological symptoms of patients and design individual care plans for each stage. Future studies should focus on developing stage-specific nursing-care protocols.

Conflict of interest

None declared.

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