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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)

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