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Eighteen Years of Resilience: A Narrative Life History Study of an Individual Undergoing Hemodialysis Therapy

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Abstract: Hemodialysis therapy for end-stage renal disease has a poor prognosis, and it is rare for hemodialysis patients to live long. However, their long-term survival is possible. We discovered a case of a patient receiving hemodialysis therapy twice a week at a health center who has survived for over 18 years. This is a rare case; therefore, the aim of this study was to explore their life experiences and analyze the positive factors of their survival. This is a qualitative narrative life history with a single participant as the respondent. The data collection was carried out through interviews using semi-structured questions. Qualitative thematic analysis was used to analyze the data. The study identified four key themes associated with patient survival factors during hemodialysis: family support, adherence to therapy and diet, appropriate levels of activity and rest, and a positive mindset.

Keywords: hemodialysis, survival, long-term therapy.

十八年的坚韧：接受血液透析治疗的个体的叙事生活史研究

摘要：终末期肾病的血液透析治疗预后不良，血液透析患者长寿的情况很少见。然而，他们长期生存是可能的。我们发现一个在健康中心每周接受两次血液透析治疗的患者已经存活了18年以上的案例。这是一个罕见的案例；因此，本研究的目的是探索他们的生活经历并分析他们生存的积极因素。这是一份定性的叙述性生活史，以一名参与者作为受访者。数据收集是通过半结构化问题的访谈进行的。使用定性主题分析来分析数据。研究确定了与血液透析期间患者生存因素相关的四个关键主题：家庭支持、坚持治疗和饮食、适当的活动和休息水平以及积极的心态。

关键词：血液透析、生存、长期治疗。

1. Introduction

The survival rate of patients undergoing hemodialysis is still meager. The study found that the survival rate for patients undergoing hemodialysis was 82.3% in the first year, 49.1% in 5 years, 22.5% in 10 years, and only 13.3% over 10 years. Their average survival time was 4.92 (3,914–5,924) (median ± interquartile range); this means that 50% of hemodialysis patients can survive for at least 4.92 years

[1–3].

Factors influencing the survival rate of patients undergoing hemodialysis vary. One of them is the patient's general health condition, comorbidities, complications, compliance with treatment, etc. [4–6]. However, hemodialysis is an intensive treatment that requires strong patient commitment. The patient's quality of life and survival can also be influenced by factors other than hemodialysis, like psychological factors, stress, and family support [7, 8].

Hemodialysis therapy for renal disease has poor prognosis. It is rare for hemodialysis patients to live long. However, long-term survival is possible for them [9]. We found a case of a patient who underwent hemodialysis therapy at a health center twice a week and has survived for more than 18 years. This study explores their life experiences and tries to disclose the factors promoting their resilience. The findings of this research are expected to be a good reference for hemodialysis services in increasing patient survival rates.

2. Methods

2.1. Study Design

The design of this research is a qualitative narrative of life history. This method focuses on collecting and analyzing stories or narratives about the lives of individuals or groups in a historical context. This design allows researchers to gain in-depth insight into the life experiences of individuals or groups in a broad historical context. It makes it possible to understand how historical events influenced their lives personally [10, 11].

2.2. Participants

Adopted from biographical research, this research only used a single participant as the respondent. This respondent was selected due to their extensive experience of undergoing hemodialysis, which other patients did not undergo [12, 13].

2.3. Data Collection

Unlike formal standard interviews, the interview here aimed to elicit a spontaneous conversation about the respondent's life history, like a daily conversation. In this way, the respondent can tell their life experiences naturally [14]. Three biographical-narrative interview steps were applied: building trust, open-ended questioning, and semi-structured interviewing to clarify certain information.

In general, the interview guide includes several questions regarding the onset of kidney failure, feelings of being diagnosed with it, the start of undergoing hemodialysis therapy, years of therapy experience, physical and psychological conditions, obstacles and challenges in doing therapy, and the encouraging factors of his hemodialysis endurance. The data collection was from January to February 2024. The interview session took 60–90 minutes and was conducted at the respondent's home. Additional interviews were conducted by phone or written chat if the information needed clarification.

2.4. Data Analysis

Thematic analysis was used in this study. The data were analyzed manually by two researchers. They discussed and shared their experiences and opinions regarding data collection and analysis. One researcher conducted the initial analysis as the interviewer, while another researcher reviewed the transcription and conducted a second analysis [15]. The results were presented in two versions, i.e., a short life history narrative and the thematic analysis results.

2.5. Ethical Considerations and Informed Consent Statement

This study received ethical approval from the Universitas Muhammadiyah Purwokerto Health Research Ethics Commission (KEPK/UMP/532/XII/2023). We also informed the respondent that this was voluntary, their identity would remain anonymous, and their information would be kept confidential. After explaining the research objectives and procedures, the respondent provided written consent. The respondent was also informed before giving consent that the interview would be recorded. The advantages and disadvantages of participating in this study were also explained.

3. Results

3.1. Narrative Life History

In this section, we explain in detail the results of the interview regarding the respondent's life experiences, from the first time he was affected by the disease to undergoing hemodialysis. The presentation is conducted in a short and comprehensive narrative.

The respondent in this study was Mr. P, who was 34 years old and suffered from chronic kidney disease. He graduated from junior high school. He is the youngest of six siblings. He comes from a low-income family and is an orphan. He lived with his older brother. He was diagnosed with chronic kidney failure at the age of 17 years. He was in junior high school at the time.

He had renal failure in 2007. At that time, he experienced problems with his kidneys and underwent treatment for 3 years. One day, there was an outbreak of chikungunya disease in his village, and he was also affected. He went to an independent practice nurse and was administered several medications. As he got home, he took the medicine. However, a few hours later, he felt nauseous, dizzy, and weak. His body felt stiff. He had convulsions and fainted. Then, his family took him to the nearest hospital emergency unit for treatment. As he improved, he was moved to the inpatient room.

From further examination, the doctor diagnosed that the patient had chronic renal failure. The doctor advised him to undergo hemodialysis immediately. He was shocked. His family continued to provide support and encouragement until he could accept his illness and the treatment he should receive.

The first five years of hemodialysis (2007-2012) were difficult. He was hospitalized frequently, approximately 20 times over the course of several years. He explained that it was possibly due to the body's adaptation to hemodialysis. The symptoms during that time included frequent nausea and vomiting, weakness, swelling, shortness of breath, and severe fatigue, all of which interfered with his daily activities. Due to these problems, he wanted to give up his life. His family always motivated him by providing support and encouragement. Hence, he could regain his life spirit.

During the next two years (2012-2014), he felt that his body accepted hemodialysis therapy; all the problems were reduced. He believed it was due to his regular hemodialysis therapies (2 times a week), medication, good diet, and enough rest. He regularly took medicine from his doctor, maintained his recommended diet (no bananas, star fruit, coconut water, coconut milk, etc.), and took sufficient time to rest.

In the following period (2014-2017), he explained that his body had stabilized; he no longer had previous problems. He could do his work as a peddler selling children's snacks. It was to help his family by providing him with treatment. He claimed that this activity inspired him to survive and motivated him to undergo hemodialysis therapy.

In his tenth year (2017), he had a terrible accident. He had a fractured spine, but the doctor reconsidered performing surgery because of his medical record. They said that the surgery poses a risk to his life. This incident had a negative impact on his psychology and behavior. He was lost in his confidence to survive. He wanted to give up and refused to undergo hemodialysis therapy. However, he said his family was always there to advise and encourage him. With their support and motivation, he was able to rise from despair.

He has gone through years of hemodialysis therapy. In 2024, he will be in his 18th year of undergoing hemodialysis. He said that many of his friends in the struggles (other hemodialysis patients) have gone. During any hemodialysis-related activities, the patient was consistently invited by nurses and hospital staff to serve as a resource person inspiring many others. He motivated them to undergo hemodialysis therapy.

At the conclusion of the interview, he offered advice to other patients undergoing hemodialysis therapy. He emphasized the importance of consistently attending hemodialysis sessions, following the prescribed diet, and taking medications as directed by their healthcare provider. Besides, psychologically, we should accept our health condition, continue enjoying life, and maintain a positive mindset. Working and other activities are essential to distract our attention from the illness. Spiritually, we also need to maintain a good connection with God, as He can only provide help and protection. Socially, he believes that it is his family support that has made him endure hemodialysis therapy for 18 years.

3.2. Thematic Analysis

In this section, we conduct a thematic analysis of the interview results regarding the respondent's life experiences. The main theme of the analysis focuses on factors that influence the patient's resilience in undergoing hemodialysis. The analysis results revealed four significant themes of resilience factors: family support, compliance therapy and diet, adequate activity and rest, and positive thinking (Fig. 1).

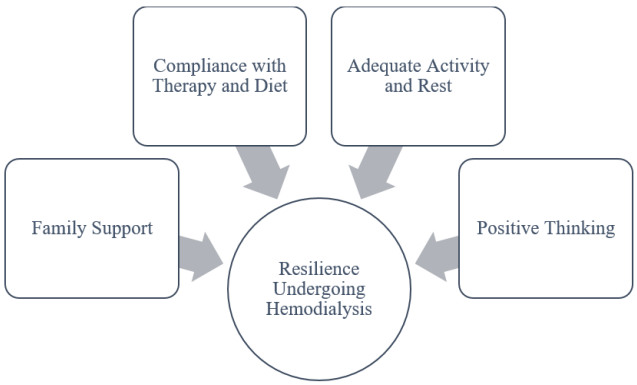

Fig. 1 Factors influencing resilience to hemodialysis therapy (The authors)

3.2.1. Theme 1: Family Support

The results of the analysis show that family support was the main factor in the respondent's resilience in undergoing hemodialysis. This is evident from the frequency with which the respondent said this, including the following statements:

"My family took me to the emergency unit for my treatment."

"At that time, I was very shocked, but my family continued supporting and encouraging me. And I could accept my illness and the treatment I should undergo."

"I wanted to give up living life, but my family always motivated me, providing support and encouragement. So that I could regain my enthusiasm for living this life again."

"I work as a peddler, selling children snacks to help my family and medical treatment because so far they have paid for my treatment."

"When I had an accident, my psychology and activities interfered with again. I also experienced a loss of confidence in surviving, and I wanted to give up and didn't want to undergo hemodialysis therapy. However, my family always advised and encouraged me so that I could rise from despair."

3.2.2. Theme 2: Compliance with Therapy and Diet

The results reveal that compliance with therapy and diet is also a factor that can increase the respondent's resilience in undergoing hemodialysis. Among them are the following:

"I routinely undergo hemodialysis twice a week."

"The key is to undergo hemodialysis therapy regularly."

"Watch your diet, don't consume bananas, star fruit, coconut water, coconut milk, etc."

"… must adhere to the diet"

3.2.3. Theme 3: Adequate Activity and Rest

The results proved that activity and rest were factors that also increased his endurance while undergoing hemodialysis. Among them are the following respondent statements:

"By working, I have more enthusiasm to survive, and I also became motivated about undergoing hemodialysis therapy."

"When I had an accident and fractured my spine, my activities were disrupted. I couldn't work; I was about to give up and didn't want to undergo hemodialysis therapy."

"I am also happy to be involved in hemodialysis-related activities in hospitals, to be a resource person who inspires many people to undergo hemodialysis therapy."

"If you are tired from work, getting enough rest is also important."

3.2.4. Theme 4: Positive Thinking

Positive thinking is also a factor that surely boosts his resilience while undergoing hemodialysis. Among them are the following respondent statements:

"You must be able to accept your health condition."

"Enjoy it."

"One must continue to think positively."

"...always have the enthusiasm to stay alive."

"Surrender yourself to Allah SWT to ask for help and protection."

4. Discussion

4.1. Family Support and Resilience in Undergoing Hemodialysis Therapy

Family support plays a vital role in helping patients undergoing hemodialysis therapy because patients usually face physical, emotional, and psychological challenges associated with their condition. They often experience stress, anxiety, and depression. Family support can help reduce this emotional burden [8, 16].

Family support can also increase patients' motivation to adhere to their treatment plan, including appropriate diet, timing of therapy, and medication management. Patients tend to be more motivated to adhere to treatment because they feel supported and loved by their families. It also improves the patient's quality of life [17, 18]. By having strong social support, patients feel more motivated, happier, and better able to overcome the challenges they face while undergoing therapy.

The family's support encompasses physical, emotional, and financial assistance. This is evident through their consistent presence during therapy sessions, prompt transportation to the hospital during emergencies, and vigilant care for the patient. Emotional support can be seen in their frequent motivation, encouragement, and reminders regarding treatment, while their financing of the treatment proves financial support. Thus, family support not only provides emotional benefits but also directly contributes to patient resilience during hemodialysis treatment.

4.2. Adherence to Therapy and Diet and Resilience in Undergoing Hemodialysis Treatment

Therapy compliance and endurance in hemodialysis therapy are closely related and mutually influence each other. The relationship between therapy compliance and resilience in hemodialysis therapy is mutually reinforcing. Good compliance increases resilience, whereas good resilience strengthens compliance, and both are positively influenced by solid social support [19, 20].

When patients adhere to the hemodialysis treatment plan recommended by the medical team, including regular therapy sessions, following an appropriate diet, and taking medications correctly, this can increase their resilience to hemodialysis therapy. Patients who consistently adhere to treatment are likely to have better outcomes and experience fewer complications, thereby increasing their resilience to the condition and treatment [21].

Similarly, high resilience can strengthen patient compliance with hemodialysis therapy. When a patient feels capable of dealing with the physical, emotional, and psychological challenges associated with treatment, they tend to be more motivated to adhere to their treatment plan. Good resilience can help reduce stress, anxiety, and discomfort during treatment, thus increasing the patient's likelihood of remaining consistent in therapy [22].

Social support, including support from family, friends, and medical personnel, is important for increasing therapeutic adherence and resilience in hemodialysis therapy. This support can help patients feel supported and motivated and better overcome challenges during treatment. Thus, social support can act as a link between compliance and resilience [20].

The level of compliance exhibited by patients in this study was impressive as they consistently adhered to a regimen of hemodialysis therapy twice a week, followed their treatment plan, and maintained adherence to the prescribed diet. With this compliance, the patient's body condition can adapt well to dialysis,

resulting in fewer complications. This made him able to survive for a long time while undergoing hemodialysis.

4.3. Activity, Rest, and Their Relationship with the Resilience in Hemodialysis Therapy

This study found that adequate activity and rest influence patient endurance in hemodialysis therapy. The patient continued to work while he was undergoing hemodialysis and became a resource person related to hemodialysis. With this work, he feels as if he forgot about the disease he suffers, thereby reducing the stress associated with hemodialysis therapy.

Activity, rest, and endurance during hemodialysis therapy influence each other. Regular physical activity, adequate rest, and a balanced daily activity pattern can help increase patient endurance during hemodialysis therapy. Adequate rest is integral to a patient's recovery after a hemodialysis session. Dialysis can cause physical and mental fatigue. Hence, adequate rest is necessary to restore energy and speed up recovery. Lack of adequate rest can reduce patient endurance during hemodialysis therapy, increase the risk of chronic fatigue, and affect the overall quality of life [23, 24].

Daily activity patterns can also influence patient endurance during hemodialysis therapy. Patients who remain physically active outside hemodialysis sessions tend to have higher energy levels, better moods, and an overall better quality of life. However, patients also need to pay attention to their physical limits and avoid activities that are too tiring because they can drain energy and interfere with the recovery process [25, 26].

4.4. Positive Thinking and Its Relationship with the Resilience of Patients Undergoing Hemodialysis Therapy

Positive thinking has a strong relationship with resilience during hemodialysis therapy. In this research, the patient has revealed his enthusiasm and acceptance of his condition; he has surrendered to God for help and protection. These are also factors that enable him to endure hemodialysis.

Positive thinking can help patients reduce the impact of stress that may arise during hemodialysis therapy. Positive thinking helps patients develop a stricter mentality and better emotional resilience when facing the challenges associated with hemodialysis therapy. By focusing on the positive aspects of situations and seeking solutions, patients can effectively manage the stress, anxiety, and uncertainty that frequently accompany treatment [27, 28].

Positive thinking can help patients maintain a more optimistic attitude and appreciate the good things in their lives, even when undergoing long-term treatment. This can improve the overall quality of life because patients are more likely to feel happy, satisfied, and grateful despite facing poor health conditions [27, 29].

Patients with a positive attitude also tend to be more motivated to remain consistent in undergoing hemodialysis therapy and adhere to their treatment plans. They see treatment as an essential part of their recovery journey and are committed to improving their health. Thus, positive thinking can help increase patient compliance with therapy [30, 31].

5. Conclusion

This study concludes that family support, compliance therapy and diet, adequate activity and rest, and positive thinking can increase the survival of hemodialysis patients. On the basis of this study's results, we present the following suggestions. The family should provide sufficient physical, emotional, and financial support so that the patient's survival is prolonged. Patients should adhere to their prescribed therapy and diet, maintain physical activity outside hemodialysis sessions, prioritize adequate rest, and cultivate a positive mindset to enhance their endurance during hemodialysis treatment.

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