



**Perceptions of illness in Hemodialysis Patients in the Reproductive Age Group:  
A cross-sectional study**

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## ABSTRACT

**Background:** The prevalence of hemodialysis patients continues to increase, especially in the productive age group, where these individuals are important contributors to the workforce. To prevent morbidity and mortality, perception is needed, especially about patient characteristics. The aim of this study was to determine the relationship between patient perceptions of disease and related characteristics in hemodialysis patients in the productive age group.

**Methods:** This research is a cross-sectional quantitative study that involved 191 purposively sampled respondents. Data collection utilized a questionnaire encompassing demographic information, and patients' perceptions of their illness were evaluated through the Brief Illness Perception Questionnaire (B-IPQ). The analysis employed the Mann-Whitney U and Kruskal Wallis H tests, with the significance level set at  $p < 0.05$ .

**Results:** The findings indicated an average perception value of  $58.53 \pm 8.455$ . A significant relationship exists between the perception of hemodialysis patients and variables such as age, gender, education level, occupation, duration of hemodialysis, and comorbidities ( $p < 0.05$ ).

**Conclusion:** Because characteristics are related to the formation of perceptions, health professionals, especially nurses, must apply a personalized approach to effectively shape positive patient perceptions. This tailored approach must take into account individual characteristics due to the diversity of patient needs.

**Keywords:** hemodialysis; patient characteristics; perceptions of illness; productive age

## ABSTRAK

**Latar Belakang:** Prevalensi pasien hemodialisis terus meningkat terutama pada kelompok usia produktif, dimana individu tersebut merupakan kontributor penting dalam angkatan kerja. Untuk mencegah terjadinya kesakitan dan kematian diperlukan persepsi terutama yang berkaitan dengan karakteristik pasien. Tujuan penelitian ini adalah untuk mengetahui hubungan persepsi pasien terhadap penyakit dan karakteristik terkait pada pasien hemodialisis kelompok usia produktif.

**Metode:** Penelitian ini merupakan penelitian kuantitatif cross-sectional yang melibatkan 191 responden yang diambil sampelnya secara purposif. Pengumpulan data menggunakan kuesioner yang mencakup informasi demografis, dan persepsi pasien terhadap penyakitnya dievaluasi melalui Kuesioner Persepsi Penyakit Singkat (B-IPQ). Analisisnya menggunakan uji Mann-Whitney U dan Kruskal Wallis H, dengan tingkat signifikansi ditetapkan pada  $p < 0,05$ .

**Hasil:** Temuan menunjukkan nilai rata-rata persepsi sebesar  $58,53 \pm 8,455$ . Terdapat hubungan yang signifikan antara persepsi pasien hemodialisis dengan variabel seperti usia, jenis kelamin, tingkat pendidikan, pekerjaan, lama hemodialisis, dan penyakit penyerta ( $p < 0,05$ ).

**Kesimpulan:** Karena karakteristik berkaitan dengan pembentukan persepsi, maka tenaga kesehatan khususnya perawat harus menerapkan pendekatan personal agar efektif membentuk persepsi positif pasien. Pendekatan yang disesuaikan ini harus mempertimbangkan karakteristik individu karena beragamnya kebutuhan pasien.

**Kata Kunci:** hemodialisis; karakteristik pasien; persepsi tentang penyakit; usia produktif

## INTRODUCTION

End-Stage Renal Disease (ESRD) is a medical condition characterized by the impaired functioning of the kidneys (Mailani et al., 2023). The prevalence of ESRD has been consistently increasing, with an estimated annual growth rate of approximately 6% to 8%, as indicated by the 2017 research conducted by Coresh. In the Indonesian context, the reported incidence of ESRD has significantly risen, increasing from about 2.0% in 2013 to 3.8% in 2018, as reported by the Indonesian Ministry of Health Research and Development Agency in 2018.

ESRD predominantly affects individuals aged between 15 and 75 years, with approximately 35% of ESRD patients falling within the 15 to 54-year age range. This specific demographic comprises a significant portion of the active workforce within society. The implications of this condition on individuals in this age group have far-reaching consequences, impacting their ability to make substantial contributions to both their families and the nation's economic well-being. Patients with End-Stage Renal Disease (ESRD) often require hemodialysis as a kidney replacement therapy (Bello et al., 2022; Webster et al., 2017). Among these hemodialysis patients, approximately 58% fall within the productive age group. As a result, government spending on hemodialysis has seen a notable increase over the years, rising from 3.2 trillion in 2016 to 5.2 trillion in 2021.

In West Sumatra, the prevalence of ESRD surpasses the national average, reaching 4% compared to the national average of 3.8%. Among the ESRD patients, approximately 15% undergo hemodialysis therapy. Moreover, West Sumatra is renowned for its local wisdom related to food, customs, and the extended family structure that impacts health perceptions and behaviors. A medical record study conducted at a hemodialysis center in West Sumatra revealed that 67.5% of patients experienced high Intradialytic Weight Gain (IDWG), while clinical laboratory results indicated poor nutrition, characterized by elevated urea and creatinine levels in 67.5% of patients.

The effectiveness of hemodialysis significantly influences patient mortality and morbidity, particularly through the clearance of urea and creatinine. Suboptimal elimination of waste products can exacerbate kidney glomerular damage and reduce patient functionality. Adherence to treatment guidelines during hemodialysis is crucial for achieving positive outcomes (Ozen et al., 2019), Non-compliance is linked to increased morbidity and mortality (Bello et al., 2022). However, it's concerning that only around 50% of patients adhere well to their treatment (Kustimah et al., 2019). In a cohort study conducted in 2017, non-compliance with treatment resulted in hospitalizations, with 1,127 admissions attributed to fluid overload, 4,321 due to cardiovascular causes, and 11,209 stemming from other reasons (Wong et al., 2017).

Various theories and research state that several factors play a role in influencing a person's behavior, especially in terms of compliance of patients undergoing hemodialysis therapy in nutritional and fluid management. Factors that can influence are perceptions of the disease (Araújo et al., 2016; Nyoman Wahyu Lestarina et al., 2022; Oliveira et al., 2023; Pratiwi et al., 2020). Illness perception is fundamentally rooted in Leventhal's Self-regulatory Model, providing a theoretical framework that elucidates how illness triggers responses from patients, subsequently influencing their coping behaviors. This model posits that patients, when confronted with symptoms, engage in a cognitive process where they assess the severity of their illness and the challenges (stressors) it presents, shaping their individual illness perception (Tanemoto et al., 2023). Therefore, personal illness beliefs are one of the prognostic factors but are potentially modifiable (Kustimah et al., 2019).

Perception plays a crucial role in the nutritional and fluid management of hemodialysis patients, as they often find nutritional requirements overly complex and conflicting with their preferences. At the onset of hemodialysis, patients commonly feel overwhelmed and struggle to control their diet (Stevenson et al., 2018). Difficulties in managing diet and fluid intake arise from patients' lack of knowledge about appropriate food choices and nutritional components to regulate (Nerbass et al., 2017). The lengthy and time-consuming hemodialysis schedule prompts them to seek practical and fast-food alternatives (Clark-Cutaia et al., 2014, 2019)

Until now, perceptions of illness have been correlated with treatment adherence (Kim et al., 2019), hopelessness (Mukadder Mollaoglu, 2016), and self-care (Kim et al., 2019). However, there is still a limited body of literature and research exploring perceptions associated with the characteristics of hemodialysis patients. Understanding these perceptions and characteristics is crucial, as determinants of adherence may vary across different populations (Clark-Cutaia et al., 2014). They can provide a foundation for targeted interventions and are essential for identifying challenges in nutrition and fluid management based on individual characteristics.

Some literature suggests that the perception of illness is associated with several factors, including age (Kim et al., 2019), gender (Salter et al., 2015), duration of hemodialysis (Kim et al., 2019) educational level (Duran et al., 2020; Strugała et al., 2019), and the presence of comorbidities (Gomez et al., 2015). For instance, older patients may experience an increase in their perception of illness due to the decline in physiological function, leading to reduced hemodialysis adequacy and a perceived futility of the treatment (Rezaiee et al., 2016). Research indicates that African American female patients tend

to exhibit a more positive attitude towards the hemodialysis experience (Salter et al., 2015). Higher education is linked to increased income, potentially fostering greater adherence to nutritional management, medication, and therapy among patients (Gerasimoula et al., 2015). Additionally, the presence of comorbidities can contribute to a perception of treatment as a burdensome and monotonous activity (Andrade et al., 2015).

Although there has been a lot of research on factors that influence patient nutrition and fluid management, perceptions of individuals in the productive age group based on their characteristics, especially in the West Sumatra region, are still limited. This study aims to assess the perception of illness in hemodialysis patients and the characteristics that influence it.

## **METHODS**

This study used a cross-sectional design with an analytical survey approach was employed, enabling researchers to assess both outcomes and exposures among the study participants concurrently. The research was conducted from July to August 2023 at four hemodialysis referral hospitals in the West Sumatra region, including M. Natsir Hospital (Solok Regency), M. Djamil Hospital (Padang Regency), Achmad Mochtar Hospital (Bukittinggi Regency), and Dr. Adnaan WD (Payakumbuh Regency).

Data obtained from the four hospitals included a total of 320 patients. Subsequently, we utilized a purposive random sampling method in line with the study's objectives. As a result, our final sample comprised 191 respondents who met the following criteria: aged between 15 and 60 years, had undergone regular hemodialysis for a minimum of 2 months, expressed willingness to participate, demonstrated conscientious awareness and cooperation, and had received proper education regarding nutrition and fluid management according to standard hospital procedures.

A demographic questionnaire gathered information on respondents' characteristics, including age, gender, education level, occupation, duration of hemodialysis, and comorbidity. Patients' perceptions of their illness were assessed using the Brief Illness Perception Questionnaire (B-IPQ), comprising nine items rated on a 0-10 scale, with one open-ended question. The total B-IPQ score ranges from 0 to 80 (Broadbent et al., 2015) and its validity, determined by Cronbach's alpha coefficient (0.812), exceeded the recommended threshold of 0.7, indicating a 95% confidence level ( $p < 0.05$ ). Sub-scale scores ranged from 0.506 to 0.816.

Statistical analysis employed IBM SPSS version 20, presenting patient characteristics through descriptive statistics (frequency, percentage, mean, median, minimum-maximum, and standard deviation). Data normality was assessed using the Kolmogorov-Smirnov test, revealing a non-normal distribution ( $p < 0.05$ ). Non-parametric tests, specifically Mann-Whitney U and Kruskal Wallis H tests, were applied to identify demographic differences in perceptions of illness, with a significance level set at  $p < 0.05$  and a confidence level of  $\alpha = 95\%$ .

## **RESULTS AND DISCUSSION**

### **RESULTS**

#### **Characteristics of respondents**

The table below presents the frequency distribution of respondents characteristics, including age, gender, education, occupation, duration of undergoing HD, and comorbidity.

| Characteristics                    | Frequency | Percentage |
|------------------------------------|-----------|------------|
| Age                                |           |            |
| 17-25 years old (late adollescent) | 8         | 4.2        |
| 26-35 years old (early addulthood) | 14        | 7.3        |
| 36-45 years old (late addulthood)  | 48        | 25.1       |
| 46-55 years old (early elderly)    | 80        | 41.9       |
| 56-60 years old (late elderly)     | 41        | 21.5       |
| Genders                            |           |            |
| Male                               | 99        | 51.8       |
| Female                             | 92        | 48.2       |
| Education                          |           |            |
| Elementary                         | 24        | 12.6       |
| Junior highschool                  | 34        | 17.8       |
| Senior highschool                  | 88        | 46.1       |
| Diploma                            | 10        | 5.2        |
| Bachelor                           | 29        | 15.2       |
| Master                             | 6         | 3.1        |
| Work                               |           |            |
| Work                               | 61        | 31.9       |
| Unemployment                       | 130       | 68.1       |
| Duration of undergoing HD          |           |            |
| < 2 years                          | 124       | 64.9       |
| ≥ 2 years                          | 67        | 35.1       |
| Comorbidity                        |           |            |
| No comorbidity                     | 8         | 4.2        |
| 1 comorbidity                      | 129       | 67.5       |
| 2 comorbidities                    | 48        | 25.1       |
| >2 comorbidity                     | 6         | 3.1        |

Table 1. Characteristics of the Respondents

The majority of respondents (41.9%) were in the 46-55 age range, categorized as early elderly. Most respondents were male (51.8%), with a predominant educational background of senior high school (46.1%). Additionally, 68.1% of the respondents were unemployed. Among the total, 125 patients (64.9%) had undergone hemodialysis (HD) for less than 2 years. The most prevalent comorbidity was a single condition (67.5%), with hypertension being the most common (45%), followed by diabetes mellitus (18.8%). A smaller percentage of patients had other comorbidities such as hepatitis B, hepatitis C, and cardiovascular disease.

Table 2 presents findings related to patient perception of illness in managing hemodialysis nutrition and fluids, while Table 3 displays differences in perception based on respondent characteristics.

| Question  | Mean ± SD     | Min | Max |
|---|---------------|-----|-----|
| How much does your illness affect your life?  | 7.78 ± 2.297  | 1   | 10  |
| How long do you think your illness will continue?   | 8.52 ± 1.994  | 1   | 10  |
| How much control do you feel you over your illness?   | 7.55 ± 1.808  | 1   | 10  |
| How much do you think your treatment can help your illness?   | 8.54 ± 1.608  | 2   | 10  |
| How much do you experience symptoms from your illness?  | 6.69 ± 1.871  | 1   | 10  |
| How concerned are you about your illness??  | 6.46 ± 2.621  | 1   | 10  |
| How well do you feel you understand your illness?   | 7.48 ± 1.692  | 2   | 10  |
| How much does your illness affect you emotionally? (e.g.does it make you angry, scared, up set or depressed?) | 5.51 ± 1.832  | 1   | 9   |
| Totally   | 58.53 ± 8.455 | 32  | 72  |

Table 2. Description of The Brief Illness Perception Questionnaire (B-IPQ) (n=191)

The table above shows that, based on the patient perception questionnaire, the highest average value was observed in the statement assessing how much do you think your treatment can help your illness. This statement illustrates that patients really hope for their therapy, namely hemodialysis.

| Characteristic                               | N   | Mean Rank | Z      | p      | df |
|--|-----|-----------|--------|--------|----|
| <b>Age<sup>a</sup></b>                       |     |           |        |        |    |
| 17-25 years old (late adolescent)            | 8   | 41.38     |        |        |    |
| 26-35 years old (early adulthood)            | 14  | 81.00     |        |        |    |
| 36-45 years old (late adulthood)             | 48  | 106.07    |        | 0.031* | 4  |
| 46-55 years old (early elderly)              | 80  | 96.14     |        |        |    |
| 56-60 years old (late elderly)               | 41  | 99.71     |        |        |    |
| <b>Gender<sup>b</sup></b>                    |     |           |        |        |    |
| Male   | 99  | 103.64    | -1.984 | 0.047* |    |
| Female                                       | 92  | 87.78     |        |        |    |
| <b>Education<sup>a</sup></b>                 |     |           |        |        |    |
| Elementary                                   | 16  | 89.06     |        |        |    |
| Junior highschool                            | 30  | 81.25     |        |        |    |
| Senior highschool                            | 89  | 89.11     |        | 0.037* | 5  |
| Diploma                                      | 23  | 118.48    |        |        |    |
| Bachelor                                     | 28  | 116.63    |        |        |    |
| Master                                       | 5   | 110.50    |        |        |    |
| <b>Occupation<sup>b</sup></b>                |     |           |        |        |    |
| Work   | 61  | 107.53    | -1.977 | 0.048* |    |
| Unemployment                                 | 130 | 90.59     |        |        |    |
| <b>Duration of undergoing HD<sup>b</sup></b> |     |           |        |        |    |
| < 2 years                                    | 124 | 101.87    | -1.999 | 0.046* |    |
| ≥ 2 years                                    | 67  | 85.13     |        |        |    |
| <b>Comorbid<sup>a</sup></b>                  |     |           |        |        |    |
| No comorbidity                               | 8   | 152.56    |        |        |    |
| 1 comorbidity                                | 129 | 90.64     |        | 0.016* | 3  |
| 2 comorbidity                                | 48  | 98.89     |        |        |    |
| >2 comorbidity                               | 6   | 112.75    |        |        |    |

Table 3. Differences in perception based on respondent characteristics (n = 191)

<sup>a</sup>Kruskal Wallis, <sup>b</sup>Mann-Whitney U, \*Significant at p < 0.05

The results indicate significant differences in perception among respondents based on age (p = 0.031), gender (p = 0.047), education (p = 0.037), employment status (p = 0.048), duration of undergoing HD (p = 0.046), and comorbidities (p = 0.016). These findings suggest that age, gender, education, occupation, duration of undergoing HD, and comorbidities may influence the perception of adult patients undergoing hemodialysis.

## DISCUSSION

The results of this research show that the average perception value is 58.53. This value is quite high when compared to the Brief Illness Perception Questionnaire (B-IPQ) which has the highest value, namely 80. If you look at the questionnaire items, all items from this perception are at values 7 and 8 when compared with the base value of 10. The highest perception There is a statement item about how the patient thinks treatment can help your disease. This statement illustrates that the patient feels confident that hemodialysis therapy can help the patient recover, but the patient also believes that the disease they suffer will not be cured and will last a lifetime.

In this research, the perceptions of hemodialysis patients were found to be influenced by several factors, including age, gender, education, occupation, duration of undergoing hemodialysis (HD), and comorbidities. The study results reveal a noteworthy correlation between the respondent's age and their perception. Older respondents exhibited a more positive perception of their illness compared to younger counterparts. This discrepancy may stem from the younger patients' confidence in

overcoming the illness without succumbing to fear, while older patients tend to demonstrate higher compliance, particularly when receiving direct services from healthcare professionals (Kim et al., 2019). These findings contrast with Gunarathne's research, which observed that, as Chronic Kidney Disease (CKD) advanced and patients underwent more dialysis cycles, middle-aged and older adult hemodialysis patients tended to develop negative thoughts toward CKD (Gunarathne et al., 2022).

Furthermore, gender plays a role in shaping perceptions. Women, in particular, tend to view the hemodialysis process as a new lifestyle and adapt more quickly than men (Rezaiee et al., 2016). The hemodialysis outcomes for female patients were also reported to be more satisfactory than those for male patients. This difference is attributed to factors such as muscle mass and physical activity, with women demonstrating better compliance in maintaining their diet compared to their male counterparts (Rezaiee et al., 2016)

The perception of disease is also associated with the duration of hemodialysis. As the length of time a patient undergoes hemodialysis increases, there is a corresponding increase in the patient's confidence in controlling the disease through treatment. Additionally, patients become accustomed to the routine of hemodialysis (Kim et al., 2019) Those who have undergone hemodialysis for an extended period tend to achieve more satisfactory results. This adaptability to the hemodialysis process and schedule instills confidence in patients, contributing to their positive experience with hemodialysis (Rezaiee et al., 2016)

Education level is another factor influencing patient perceptions. Patients with a higher level of education exhibit increased compliance, as their better understanding of the disease contributes to adherence to treatment regimens (Strugała et al., 2019). Additionally, education level plays a role in the psychological resilience of patients undergoing hemodialysis, impacting their persistence in the treatment process (Duran et al., 2020). Higher-educated patients tend to enjoy a better quality of life due to a deeper comprehension of the disease and greater adherence to treatment regimens. Moreover, higher education levels are associated with increased income, leading to greater compliance with nutritional management, medication, and therapy (Gerasimoula et al., 2015)

The presence of comorbidities accompanying the patient's illness significantly influences their perception. Patients perceive comorbidities as crucial factors that can worsen their condition (Gomez et al., 2015; Luo et al., 2020). However, they believe that undergoing regular hemodialysis can contribute to improvement compared to not undergoing any treatment. Patients assume that consistent hemodialysis can also positively impact comorbidities (Dahlerus et al., 2016).

The following analysis of the aforementioned research results reveals the profound impact of this disease on patient productivity. Approximately 31.9% of patients are still capable of working, while the majority are no longer able to do so. Consequently, despite having only one comorbidity at present, if the patient's perception of the disease turns negative, it may lead to various complications.

## **LIMITATIONS OF THE STUDY**

Data collection for this research presented challenges, as patients often preferred to rest. As a result, researchers had to carefully schedule and coordinate interviews with the patients

## **CONCLUSIONS AND SUGGESTIONS**

The results of this study found that perceptions of hemodialysis patients were related to patient characteristics (age, gender, education, employment status, length of treatment, comorbidities). These findings indicate that age, gender, education, employment, length of time undergoing HD, and comorbidities can influence the perception of adult patients undergoing hemodialysis. Health

workers, especially nurses, should implement a specially designed approach to positively influence patient perceptions by considering individual characteristics, as these perceptions are very important in managing nutritional and fluid intake. Monitoring may prove to be an effective strategy, considering the diverse needs of patients.

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## ETHICAL CONSIDERATIONS

This research obtained ethical approval (Approval number: 190/KEPK/2021) from the Health Research Ethics Committee at M Djamil Padang Central General Hospital. Prior to their participation, patients gave informed consent, which included comprehensive details about the research objectives, procedures, confidentiality, and the option to withdraw from the study. This procedure guaranteed that patients were adequately informed and participated voluntarily, respecting their autonomy and rights.

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## CONFLICT OF INTEREST STATEMENT

The authors declare that there were no financial or commercial conflicts of interest during the course of this study, and they have no competing interests with the funding sources.

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