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The Relationship between Health Literacy, Illness Perception, and Self-Management Adherence among Hemodialysis Patients in Indonesia

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ABSTRACT

Hemodialysis patients' self-management is critical for maintaining their quality of life and minimizing complications. Patients' health literacy and perception of the disease are essential for their acceptance of the condition and treatment. However, the relationship between these variables and self-management among hemodialysis patients remains unclear. This study aims to identify the relationship between health literacy, perception of disease, and self-management among hemodialysis patients. This correlational study was cross-sectional design, with 129 hemodialysis patients consecutively recruited from a hemodialysis unit of a tertiary hospital in West Java, Indonesia. Data were collected using the Brief-Illness Perception Questionnaire (Brief-IPQ), the European Health Literacy Survey Questionnaire (HLS-EU-Q47), and the End Stage Renal Disease Adherence Questionnaire (ESRD-AQ). The data were analyzed using Pearson correlation analysis. Most of the patients had sufficient or excellent health literacy (74.4%), negative illness perception (50.4%), and low self-management practices (71.3%). Pearson's correlation analysis revealed a positive correlation was found between health literacy and self-management practices ($r = .189$; $\rho=0.032$). Additionally, there was a negative correlation between illness perception and health literacy ($r = -.27$; $\rho= .002$) as well as between illness perception and self-management practices ($r = -.762$; $\rho= .000$). Positive illness perception and better self-management practices correlate with a higher level of health literacy. These findings highlight the importance for healthcare staff to facilitate positive illness perceptions and self-management practices, and to consider these factors as vital aspects in developing self-management education programs for ESRD patients.

Key Messages:

- Positive illness perception and better self-management practices correlate with a higher level of health literacy.
- Healthcare workers should provide interventions to enhance health literacy and patients' perceptions of disease, thereby improving adherence to self-management.

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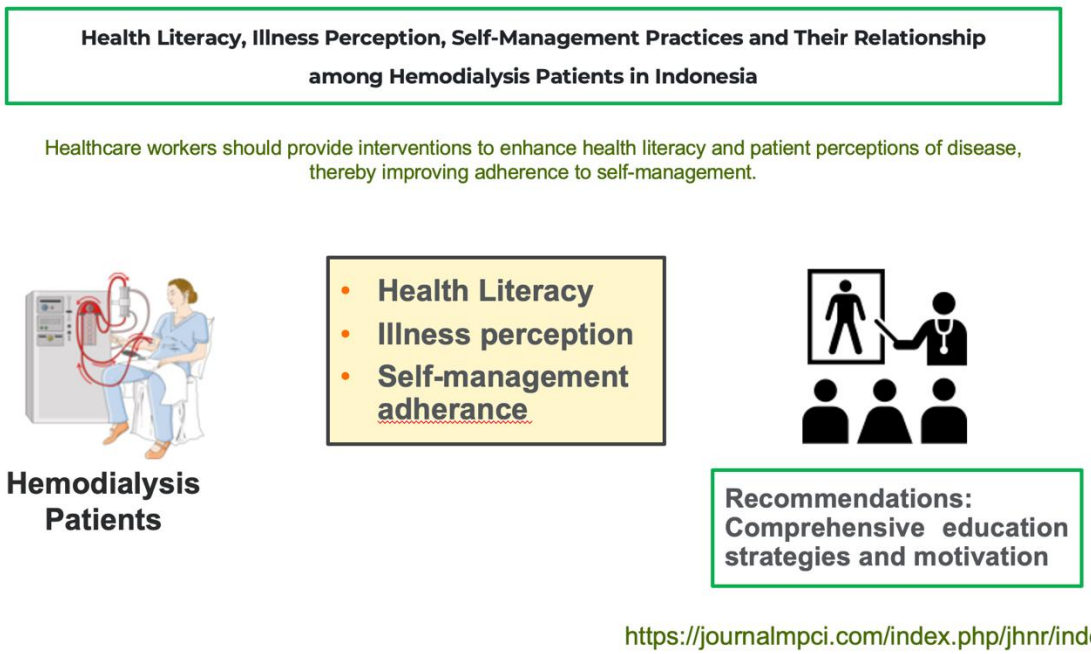
GRAPHICAL ABSTRACT



INTRODUCTION

Chronic kidney failure is a non-communicable disease that continues to increase worldwide. In 2013, the number of new cases of chronic kidney failure in the United States reached 117,162, an increase from 2012, which saw 363 new cases per million people per year (1). Similarly, the incidence of chronic kidney failure in Indonesia has been rising. According to the Regional Health Research (Riskesdas) data in 2018, the prevalence of chronic kidney failure among individuals over 15 years old reached 3.8‰ (2). In 2020, the Indonesian Renal Registry (IRR) reported 61,789 newly diagnosed chronic kidney failure patients and 130,931 active patients (3).

Patients with end-stage renal failure experience various symptoms caused by impaired kidney function, such as dysuria or anuria, edema, shortness of breath, ascites, anemia, pruritus, and more. In addition to physical symptoms, hemodialysis patients often face psychological symptoms like anxiety and depression (4). To manage these issues, patients with end-stage renal failure must undergo renal replacement therapy, primarily hemodialysis in Indonesia, which reached 1,243 patients in 2015 (3). Without treatment, patients may suffer from acid-base disorders, which can be fatal (5).

Hemodialysis patients are required to adhere to various treatments, including regular hemodialysis sessions, prescribed medications, fluid intake restrictions, and dietary control. Numerous studies indicate that most hemodialysis patients struggle with adhering to fluid and sodium restrictions (5). Excessive fluid intake can lead to weight gain, adversely affecting the patient's condition, such as increased blood pressure (6). Non-adhere with therapy not only worsens patients' health but also leads to economic losses (7), as the cost of treatment escalates with deteriorating conditions.

To maintain their health, hemodialysis patients must practice proper self-management. Van De Velde et al. define self-management as daily activities that contribute to long-term health and well-being (8). Hemodialysis patients who are not compliant in carrying out self-management can cause a decline in their health condition (9). Self-management is crucial in managing chronic diseases, enhancing well-being, health, and physical and emotional stability (10,11). Hemodialysis patients are expected to manage their health by limiting fluid and sodium intake, controlling their diet, engaging in appropriate physical activity, and managing stress.

Good health literacy is essential for hemodialysis patients to effectively engage in self-management. Health literacy plays a vital role in health care, disease prevention, and health promotion. It involves the patient's ability to find, understand, evaluate, and use health information. Knowledge forms

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the basis for behavior, and behavior rooted in adequate knowledge tends to be more sustainable. Many hemodialysis patients need sufficient knowledge about diet, complications, and prevention methods (12). Patients with high health literacy can improve their knowledge, decision-making abilities, and self-management behaviors (13).

In addition to health literacy, a patient's perception of their disease significantly influences their behavior during treatment. Illness perception refers to a patient's beliefs about their disease (14). Negative perceptions can increase morbidity and mortality, decrease quality of life, and lead to non-adherence to medical therapies among hemodialysis patients (15). Conversely, positive thinking about interventions can enhance hope and adherence to treatment (16). Perceptions influence cognitive and emotional responses, shaping coping mechanisms and planning to manage the illness. Hemodialysis patients with a positive perception of their disease can better control interdialytic weight gain (17).

Health workers play a crucial role in assisting hemodialysis patients with self-management. They must implement various interventions to enhance patients' self-management abilities. Given the importance of self-management in hemodialysis patients and the influence of health literacy and illness perception on adherence, research is needed to explore the relationship between these factors and self-management practices.

METHODS

This research used cross sectional study design. This descriptive correlational study aimed at identifying the relationship between health literacy, disease perception, and adherence to self-management among hemodialysis patients. The target population consisted of chronic kidney disease (CKD) patients undergoing hemodialysis at a type A hospital in Indonesia. On average, 129 patients visit this hospital per month. The sampling technique used in this research was consecutive sampling. After obtaining permission from the hospital and ethical approval, the researcher approached eligible patients with the assistance of the head nurse of the hemodialysis unit. The inclusion criteria were kidney failure patients undergoing hemodialysis with stable vital signs. The exclusion criteria were patients who had just undergone their first hemodialysis session. The research was conducted only on patients who had undergone hemodialysis more than once, as measuring self-management in patients undergoing their first session would be challenging. Patients were informed about the research aims and procedures, and those willing to participate were asked to sign an informed consent form. Participants were recruited until the target of 129 was reached.

The variables in this study included health literacy, disease perception, and adherence to self-management among hemodialysis patients. The three variables are mutually independent of each other. This study will examine the relationship between these three variables. The instrument used to measure patient health literacy in this study was the European Health Literacy Survey Questionnaire (HLS-EU-Q47), developed by the Health Literacy Consortium. It consists of 47 questions using a Likert scale with values ranging from 0 to 5. Patient health literacy was categorized as inadequate (0–25), problematic (26–33), moderate (34–42), and sound (43–50) (18). This questionnaire has been translated into Indonesian (19).

Perceptions of disease among hemodialysis patients were identified using the Brief Illness Perception Questionnaire (Brief-IPQ). Respondents rated their perceptions from 1 to 10 on eight questions and provided one open-ended response about the three causes of the disease they believed most. Higher scores indicated more negative perceptions (20). Negative illness perception is the patient's negative emotional reaction to their illness (21). This questionnaire has been validated for use with CKD patients (22), and the Bahasa Indonesia version has been proven valid and reliable (23).

To identify patient adherence in self-management, the End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ) was used. This questionnaire consists of five sections: general information, hemodialysis measures, medication, fluids, and diet. This questionnaire consists of 46 questions, which have different points for every item (from no value to 50, 100, 150, and 200). The minimum total score is 0, and the maximum is 1200. Higher scores indicate better patient compliance. The ESRD-AQ has been validated, showing an average item-level content validity index (I-CVI) of 0.99 and intra-class correlation coefficients (ICCs) ranging from 0.83 to 1.00 (24,25). The questionnaire used in this research was back-translated into Indonesian and underwent face validity assessment.

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Data were collected by asking the respondents to complete a questionnaire while undergoing or waiting for hemodialysis. Respondents filled out the questionnaire themselves, with the researcher available to provide explanations if they needed help understanding the questions. The variables in this research, such as health literacy, perceptions of hemodialysis patients, and compliance with self-management, were treated as ordinal variables. The relationship between health literacy, perception of illness, and patient adherence to self-management was tested using pearson correlation analysis using numerical data in each variable.

CODE OF HEALTH ETHICS

This research received ethical approval from Universitas Padjadjaran's Research Ethics Commission (No. 591/UN6.KEP/EC/2018). After gaining ethical approval, the researcher, assisted by the head nurse of the hemodialysis unit, approached eligible patients. The researcher explained the research procedures and sought informed consent from the respondents.

RESULTS

Respondent characteristic data included age, occupation, educational level, and length of time undergoing dialysis. Most respondents were over 45 years old (65.11%, (M+SD = 49.08+12.14)), unemployed (73.64%), had a senior high school education (38%), and had undergone dialysis for 1 to 5 years (48.84%, (M+SD = 4.18+ 0.071)). Hemodialysis patient health literacy, illness perception, and self-management adherence based on respondent characteristics are presented in Table 1. Respondents aged ≤45 years, 77.4% had excellent health literacy, 53.3% had negative perceptions of the disease, and 77.8% had low adherence in carrying out self-management. Of respondents aged > 45 years, 72.6% had good health literacy, 51.2% had positive perceptions of the disease, and 67.9% had low adherence in carrying out self-management. 73.5% of respondents who worked had excellent health literacy, 58.8% had negative perceptions of the disease, and 83.3% had high adherence in carrying out self-management. 74.7% of unemployed respondents had good health literacy, 52.6% had a positive perception of the disease, and 82.4% had low adherence in carrying out self-management. 65.2% of respondents who underwent hemodialysis for ≤5 years had excellent health literacy, 50% had a positive perception of the disease, and 72.7% had low adherence in carrying out self-management. 84.1% of respondents who underwent hemodialysis for >5 years had good health literacy, 50.8% had negative perceptions of the disease, and 69.8% had low adherence in carrying out self-management.

Table 1. Respondents' characteristics and their correlation with health literacy, illness perception, and self-management practices

Characteristics	N (%)	Health Literacy (median: 27.85 min: 22.22 max: 34.72)		Illness Perception (median: 44 min: 35 max: 54)		Self-management Adherence (median: 1000 min: 750 max: 1150)	
		Sufficient n (%)	Excellent n (%)	Negative n (%)	Positive n (%)	Low n (%)	High n (%)
Age (M±SD = 49.08±12.14)							
≤ 45 years old	45 (34.88)	10 (22.2)	35 (77.4)	24 (53.3)	21 (46.7)	35 (77.8)	10 (22.2)
> 45 years old	84 (65.11)	23 (27.4)	61 (72.6)	41 (48.8)	43 (51.2)	57 (67.9)	27 (31.2)
Total	129 (100)	33 (25.6)	96 (74.4)	65 (50.4)	64 (49.6)	92 (71.3)	37 (28.7)
Occupation							
Actively work	34 (26.36)	9 (26.5)	25 (73.5)	20 (58.8)	14 (41.2)	28 (82.4)	6 (17.6)
Unemployed	95 (73.64)	24 (25.3)	71 (74.7)	45 (47.4)	50 (52.6)	64 (67.4)	31 (83.8)
Total	129 (100)	33 (25.6)	96 (74.4)	65 (50.4)	64 (49.6)	92 (71.3)	37 (28.7)
Educational Level							
Elementary	36 (27.91)	13 (36.1)	23 (63.9)	17 (47.2)	19 (52.8)	27 (75)	9 (25)
Junior High school	28 (21.71)	6 (21.4)	22 (78.6)	11 (39.9)	17 (60.7)	16 (57.1)	12 (42.9)
Senior high school	49 (38)	9 (18.4)	40 (81.6)	23 (46.9)	26 (53.1)	33 (67.3)	16 (32.7)
University	16 (12.4)	5 (31.2)	11 (68.8)	14 (87.5)	2 (12.5)	16 (100)	0 (0)

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Characteristics	N (%)	Health Literacy (median: 27.85 min: 22.22 max: 34.72)		Illness Perception (median: 44 min: 35 max: 54)		Self-management Adherence (median: 1000 min: 750 max: 1150)	
		Sufficient n (%)	Excellent n (%)	Negative n (%)	Positive n (%)	Low n (%)	High n (%)
Total	129 (100	33 (25.6)	96 (74.4)	65 (50.4)	64 (49.6)	92 (71.3)	37 (28.7)
Length of Hemodialysis (M+SD = 4.18+ 0,071)							
≤ 5 years	66 (51.16)	23 (34.8)	43 (65.2)	33 (50)	33 (50)	48 (72.7)	18 (27.3)
> 5 years	63 (48.84)	10 (15.9)	53 (84.1)	32(50.8)	31(49.2)	44 (69.8)	19 (30.2)
Total	129 (100)	33 (25.6)	96 (74.4)	65(50,4)	64(49.6)	92 (71.3)	37 (28.7)

Table 2 show that the relationship between health literacy, perceptions of disease, and patient adherence to self-management. According to the data in Table 2, there is a relationship between health literacy and adherence to self-management. Further analysis found a positive correlation between patients' health literacy and self-management practices (r=.189; ρ=.032). Additionally, a negative correlation was found between patients' health literacy and illness perception (r = -.27; ρ=.002) and between patients' illness perception and self-management practices (r = -.762; ρ=.000). This indicates that patients with higher health literacy and a more positive perception of illness tend to report better self-management practices. Patients with higher health literacy also tend to have more positive illness perceptions (Table 2). Furthermore, there is a correlation between the perception of illness and adherence to patient self-management. The Pearson correlation between perception and adherence is negative, indicating that a higher perceived value corresponds to a more negative patient perception. This contrasts with adherence, where a higher perceived value indicates better adherence.

Table 2. Relationship between patients' health literacy, illness perception, and self-management practices (n = 129)

Correlation	r	p
Health literacy and Illness perception	-.27	.002
Health literacy and Self-management adherance	.189	.032
Illness perception and Self-management adherance	-.762	.000

DISCUSSION

Hemodialysis can cause various physical signs and symptoms. According to the Kidney Disease Improving Global Outcomes (KDIGO) guidelines, the glomerular filtration rate (GFR) is used to assess kidney damage and determines the severity of these signs and symptoms (26). The patient's age is another contributing factor. Hemodialysis patients may experience anemia, fatigue, anxiety, decreased concentration, disorientation, tremors, weakness in the arms, pain in the soles of the feet, and changes in behavior. To manage these symptoms, hemodialysis patients must undergo various treatments, including hemodialysis, medication, fluid and dietary restrictions (27).

Hemodialysis patients need to engage in self-management practices to ensure their treatment aligns with their expectations and goals. Self-management involves individuals, families, or communities promoting health, preventing disease, maintaining health, and coping with illness and disability, with or without support from healthcare workers. This includes health promotion, disease prevention and control, self-medication, providing care to dependent individuals, seeking help from healthcare workers, and rehabilitation, including palliative care (28).

According to the research results, the majority of respondents were not adhering to the self-management schedule. Patient adherence to the schedule for carrying out hemodialysis is good. The most challenging thing for hemodialysis patients to do is limit fluid intake. Patients perceive that controlling their thirst is more difficult than controlling their food intake. According to the doctor's recommendations, medication compliance for hemodialysis patients is still lacking. Hemodialysis patients often find it difficult to consume large amounts of medication, even though, on the other hand, they have to maintain fluid intake.

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Various factors, including knowledge, self-efficacy, social support, and depression, influence hemodialysis patients' ability to carry out self-management (29).

Most hemodialysis patients did not adhere adequately to self-management, which can result in worsening conditions, the emergence of complications, and a decreased quality of life. Therefore, implementing various interventions to enhance patient adherence is essential. Emotional support, patient education about treatment and care, as well as regular health progress evaluations are strategies that should be implemented to enhance patient self-management. This can improve the cooperation between patients and healthcare professionals (30).

Based on this study's data, there is a relationship between health literacy and adherence in self-management (r=.189). This result is similar to another study among chronic kidney disease patients in Pakistan (31). There is a positive correlation between health literacy and medication adherence (r = 0.024). The differences in the r value can relate to a larger sample size or different population cultures. Health literacy involves a person's ability to search for, process, and understand basic health information and services. It plays a crucial role in healthcare, disease prevention, and health promotion. Health literacy includes the patient's ability to find health information, understand and evaluate it, and use it effectively (32). Health literacy includes three major elements: knowledge about health, health services, and health systems; processing and using information in various formats related to health and health services; and the ability to maintain health through self-management and collaboration with health care providers (33). Patients with good health literacy tend to be more adherence in self-management.

Based on the research results, the majority of respondents in this study had moderate health literacy. A person's level of health literacy can influence their health condition (34). Various social and cultural factors, such as personal beliefs, value systems, and traditions, can influence a person's health literacy, perception, and acceptance of health information (35). The ability of hemodialysis patients to carry out self-management is influenced by several factors, including knowledge (36). Knowledge is the basis for determining behavior, and behavior based on adequate knowledge tends to be sustainable. Patients can acquire knowledge if they are able to locate and comprehend health information, which enhances their self-management abilities.

The patient's last education can affect their adherence to self-management. Low health literacy frequently occurs in patients who are elderly, have low education, or come from low socioeconomic communities. Most patients get health information from doctors and other health workers. In addition, there are other sources of information, such as pamphlets, the internet, books, and other patients. The elderly often experience decreased cognitive abilities, affecting their capacity to find, understand, and use health information.

Patient education can affect the patient's health literacy (37). This study indicates that the patient's health literacy can influence their adherence to self-management. Patients with higher education have greater access to information sources and engage in more discussions with healthcare workers. Most respondents had completed senior high school, a higher level of education than basic education in Indonesia. This educational background enables patients to access various health information sources and understand the health information they receive.

The study revealed a significant relationship between patient adherence to self-management and perceptions of disease (r=.762). This is similar with another study that a negative correlation between illness perception and medication adherence (r = −0.061) (31). Adherence in their study specific to medication adherence. This is related with differences r value.

Hemodialysis patients' perception of disease is critical, as it impacts treatment adherence, functional improvement, and quality of life. Patients perceive their condition through cognitive and emotional responses to symptoms and disease. Their understanding and acceptance of the disease affect their coping and adaptation (38). When faced with a disease, an individual tends to respond in a specific way. Understanding patients' beliefs about their disease and necessary treatment helps them provide adaptive responses. The patient's perception of the disease forms the basis for developing treatment goals to improve adaptive function (39).

Most respondents in this study had a negative perception of their disease. Negative perceptions

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can worsen their condition and affect their quality of life. Factors such as the patient's experience or knowledge of medical intervention and their condition status influence their perception. Short procedures can increase patients' knowledge and confidence in carrying out treatment (40). Although most respondents had been on dialysis for 1–5 years and should have a positive perception, the differences between patients with positive and negative perceptions were minimal. Education level, such as high school or equivalent education, influences patients' knowledge about their disease and treatment.

Hemodialysis patients face various stressors related to their disease and treatment. Diet and fluid restrictions are challenging, and patients may perceive personal, social, and systemic barriers affecting adherence. Additionally, most patients do not receive sufficient support in managing diet and fluid restriction (41). Hemodialysis patients also frequently experience stressors such as itching, weakness, psychological disorders, feelings of uncertainty about the future, guilt towards family, and other social problems (42). Psychological disorders, including depression, anxiety, sadness, low self-esteem, sleep disorders, and pessimism about the future, are common among hemodialysis patients (43). These conditions affect patients' emotional status and acceptance of the disease and its treatment, as well as interpersonal relationships within the family and social life. A large number of respondents with negative perceptions of the disease can increase morbidity and mortality rates, reduce quality of life, and lead to non-compliance with medical therapies (44). This impacts treatment outcomes for hemodialysis patients. Therefore, patients require social and family support to enhance their acceptance of the disease and its treatment.

Healthcare workers, especially nurses, should help patients improve their health literation and perception of their illness. Programs carried out by nurses to improve patients' perceptions, such as counseling and peer group activities, can be beneficial. There are many interventions that can improve knowledge and health literacy such as teach-back methods. The strength of this study lies in its focus on hemodialysis patients, measuring the relationship between health literacy, illness perception, and self-management adherence. However, the study has limitations, including the use of a self-management adherence instrument in Bahasa Indonesia that lacks construct validity and reliability testing.

CONCLUSION

Hemodialysis patients must engage in self-management for effective treatment. This study describes higher health literacy and more positive illness perception correlating with better self-management. Non-adherence with self-management can lead to deteriorating conditions and decreased quality of life. Healthcare workers should provide interventions to enhance health literacy and patient perceptions of disease, thereby improving adherence to self-management. Comprehensive education strategies and motivation can serve as effective interventions.

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CONFLICTS OF INTEREST

The author declares no conflict of interest.

REFERENCES

1. Usrds. 2017 USRDS Annual Data Report: Executive Summary [Internet]. [cited 2018 Dec 6]. Available from: https://www.usrds.org/2017/download/2017_Volume_1_CKD_in_the_US.pdf

https://doi.org/10.56303/jhnresearch.v4i2.401

2. Kementerian Kesehatan Republik Indonesia. Laporan Nasional Riskesdas 2018. 2019 [cited 2024 Mar 24]; Available from: https://repository.badankebijakan.kemkes.go.id/id/eprint/3514/1/Laporan%20Riskesdas%202018%20Nasional.pdf
3. 3 th Annual Report Of Indonesian Renal Registry 2020. [cited 2024 Jun 3]; Available from: www.indonesianrenalregistry.org
4. Nagy E, Tharwat S, Elsayed AM, Shabaka SAEG, Nassar MK. Anxiety and depression in maintenance hemodialysis patients: prevalence and their effects on health-related quality of life. Int Urol Nephrol [Internet]. 2023 Nov 1 [cited 2024 Jun 13];55(11):2905. Available from: /pmc/articles/PMC10560136/
5. Sukartini T, Efendi F, Putri NS. A phenomenological study to explore patient experience of fluid and dietary restrictions imposed by hemodialysis. Journal of Vascular Nursing. 2022 Jun 1;40(2):105–11.
6. Loutradis C, Sarafidis PA, Ferro CJ, Zoccali C. Volume overload in hemodialysis: diagnosis, cardiovascular consequences, and management. Nephrology Dialysis Transplantation [Internet]. 2021 Dec 1 [cited 2024 Jun 9];36(12):2182. Available from: /pmc/articles/PMC8643589/
7. Himmelfarb J, Vanholder R, Mehrotra R, Tonelli M. The current and future landscape of dialysis. Nat Rev Nephrol [Internet]. 2020 Oct 1 [cited 2024 Jun 13];16(10):573. Available from: /pmc/articles/PMC7391926/
8. Van De Velde D, De Zutter F, Satink T, Costa U, Janquart S, Senn D, et al. Delineating the concept of self-management in chronic conditions: a concept analysis. BMJ Open [Internet]. 2019 Jul 1 [cited 2024 Jun 9];9(7). Available from: /pmc/articles/PMC6661649/
9. Yasin F, Khraim F, Santos M, Forgrave D, Hamad A. Factors influencing self-care management in adult hemodialysis patients: An integrative review. Qatar Med J [Internet]. 2024 [cited 2025 Apr 27];2024(1):12. Available from: https://pmc.ncbi.nlm.nih.gov/articles/PMC11037095/
10. Moreels T, Van de Velde D, Goethals J, Vanden Wyngaert K, De Baets S, Nagler E, et al. Self-Management Interventions for Facilitating Life Participation for Persons with Kidney Failure A Systematic Review. Clinical Journal of the American Society of Nephrology [Internet]. 2024 Feb 1 [cited 2024 Jun 13];19(2):189–201. Available from: https://journals.lww.com/cjasn/fulltext/2024/02000/self_management_interventions_for_facilitating.10.aspx
11. Riegel B, Jaarsma T, Strömberg A, Clemmer E, Chair S. A Middle-Range Theory of Self-Care of Chronic Illness. 2012 [cited 2018 Dec 6];3(35):194–204. Available from: http://dx.doi.org/10.1097/ANS.0b013e318261b1bahttp://www.lww.com/http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-81836
12. Xu F, Zhuang B, Wang Z, Wu H, Hui X, Peng H, et al. Knowledge, attitude, and practice of patients receiving maintenance hemodialysis regarding hemodialysis and its complications: a single-center, cross-sectional study in Nanjing. BMC Nephrol [Internet]. 2023 Dec 1 [cited 2024 Jun 9];24(1). Available from: /pmc/articles/PMC10510168/
13. Boonstra MD, Reijneveld SA, Foitzik EM, Westerhuis R, Navis G, de Winter AF. How to tackle health literacy problems in chronic kidney disease patients? A systematic review to identify promising intervention targets and strategies. Nephrology Dialysis Transplantation [Internet]. 2021 Jul 1 [cited 2024 Jun 9];36(7):1207. Available from: /pmc/articles/PMC8237988/
14. Muscat P, Weinman J, Farrugia E, Camilleri L, Chilcot J. Illness perceptions predict mortality in patients with predialysis chronic kidney disease: a prospective observational study. BMC Nephrol [Internet]. 2020 Dec 1 [cited 2024 Jun 9];21(1). Available from: /pmc/articles/PMC7727218/
15. Alharbi AA, Alharbi YA, Alsobhi AS, Alharbi MA, Alharbi MA, Aljohani AA, et al. Impact of Illness Perception on the Health-Related Quality of Life of Patients Receiving Dialysis: A Cross-Sectional Study. Cureus [Internet]. 2021 Jun 17 [cited 2024 Jun 9];13(6). Available from: /pmc/articles/PMC8285669/

https://doi.org/10.56303/jhnresearch.v4i2.401

16. Sabouri F, Rambod M, Khademian Z. The effect of positive thinking training on hope and adherence to treatment in hemodialysis patients: a randomized controlled trial. BMC Psychol [Internet]. 2023 Dec 1 [cited 2024 Jun 13];11(1). Available from: /pmc/articles/PMC9830796/
17. Kim S, Kim E, Ryu E. Illness Perceptions, Self-Care Management, and Clinical Outcomes According to Age-Group in Korean Hemodialysis Patients. Int J Environ Res Public Health [Internet]. 2019 Nov 2 [cited 2024 Jun 9];16(22). Available from: /pmc/articles/PMC6888085/
18. Sørensen A, den Broucke V. Measuring health literacy in populations: illuminating the design and development process of the European Health Literacy Survey Questionnaire (HLS-EU-Q) Item Type Journal Article. Citation BMC Public Health [Internet]. 2013 [cited 2024 Jun 11];13(1):948. Available from: http://dx.doi.org/10.1186/1471-2458-13-948
19. Rachmani E, Hsu CY, Nurjanah N, Chang PW, Shidik GF, Noersasongko E, et al. Developing an Indonesia's health literacy short-form survey questionnaire (HLS-EU-SQ10-IDN) using the feature selection and genetic algorithm. Comput Methods Programs Biomed [Internet]. 2019 Dec 1 [cited 2024 Jun 11];182. Available from: https://pubmed.ncbi.nlm.nih.gov/31518767/
20. Broadbent E, Wilkes C, Koschwanez H, Weinman J, Norton S, Petrie KJ. A systematic review and meta-analysis of the Brief Illness Perception Questionnaire. Psychol Health [Internet]. 2015 [cited 2018 Nov 4];30(11):1361–85. Available from: http://dx.doi.org/10.1080/08870446.2015.1070851
21. Wu H, Zhao X, Fritzsche K, Salm F, Leonhart R, Jing W, et al. Negative illness perceptions associated with low mental and physical health status in general hospital outpatients in China. Psychol Health Med [Internet]. 2014 May 4 [cited 2025 Apr 25];19(3):273–85. Available from: https://pubmed.ncbi.nlm.nih.gov/23721418/
22. Rivera E, Levoy K, Clark-Cutaia MN, Schrauben S, Townsend RR, Rahman M, et al. Content Validity Assessment of the Revised Illness Perception Questionnaire in CKD Using Qualitative Methods. Int J Environ Res Public Health [Internet]. 2022 Jul 1 [cited 2024 Jun 11];19(14). Available from: https://pubmed.ncbi.nlm.nih.gov/35886505/
23. Rias YA, Abiddin AH, Huda N, Handayani S, Sirait HS, Pien LC, et al. Psychometric Testing of the Bahasa Version of the Brief Illness Perception Questionnaire among Indonesians with Type 2 Diabetes Mellitus. Int J Environ Res Public Health [Internet]. 2021 Sep 1 [cited 2024 Jul 17];18(18). Available from: /pmc/articles/PMC8469354/
24. Kim Y, Evangelista LS, Phillips LR, Pavlish C, Kopple JD. The End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ): Testing The Psychometric Properties in Patients Receiving In-Center Hemodialysis. Nephrol Nurs J [Internet]. 2010 Jul [cited 2024 Jul 17];37(4):377. Available from: /pmc/articles/PMC3077091/
25. Evangelista LS, Phillips LR, Pavlish C, Kopple JD. The End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ): Testing The Psychometric Properties in Patients Receiving [Internet]. [cited 2018 Dec 3]. Available from: https://cloudfront.escholarship.org/dist/prd/content/qt0sf9v9qk/qt0sf9v9qk.pdf?t=oo9n0t
26. Vaidya SR, Aeddula NR. Chronic Kidney Disease. The Scientific Basis of Urology, Second Edition [Internet]. 2022 Oct 24 [cited 2024 Jun 11];257–64. Available from: https://www.ncbi.nlm.nih.gov/books/NBK535404/
27. Melastuti E, Nursalam N, Sukartini T, Putra MM. Self-care Adherence in Hemodialysis Patients: A Structural Equation Modeling. Open Access Maced J Med Sci. 2022 Apr 15;10(B):1107–12.
28. World Health Organization. Self care for health: a handbook for community health workers & volunteers. 2017;
29. Gela D, Mengistu D. Self-management and associated factors among patients with end-stage renal disease undergoing hemodialysis at health facilities in Addis Ababa, Ethiopia. Int J Nephrol Renovasc Dis. 2018;11:329–36.
30. purba agavia kristi, Emaliyawati E, Sriati A. Self-Management and Self-Efficacy In Hemodialysis Patients. Journal of Nursing Care [Internet]. 2018 Jul 3 [cited 2024 Jun 11];1(2). Available from: https://jurnal.unpad.ac.id/jnc/article/view/16137

https://doi.org/10.56303/jhnresearch.v4i2.401

31. Hamza MA, Ullah S, Ahsan H, Ali W, Masud M, Ahmed A. Health literacy, illness perception, and their association with medication adherence in end-stage renal disease. Int Urol Nephrol [Internet]. 2025 Apr 4 [cited 2025 May 14];1–16. Available from: https://link.springer.com/article/10.1007/s11255-025-04472-8
32. Koenig T. IHS Political Science Series Working Paper 146 Managing Policy: Executive Agencies of the European Commission [Internet]. 2017 [cited 2018 Dec 3]. Available from: http://irihs.
33. Liu C, Wang D, Liu C, Jiang J, Wang X, Chen H, et al. What is the meaning of health literacy? A systematic review and qualitative synthesis. Fam Med Community Health [Internet]. 2020 May 14 [cited 2024 Jun 11];8(2). Available from: /pmc/articles/PMC7239702/
34. Shahid R, Shoker M, Chu LM, Frehlick R, Ward H, Pahwa P. Impact of low health literacy on patients' health outcomes: a multicenter cohort study. BMC Health Serv Res [Internet]. 2022 Dec 1 [cited 2024 Jun 11];22(1):1–9. Available from: https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-022-08527-9
35. Shaw SJ, Huebner C, Armin J, Orzech K, Vivian J. The role of culture in health literacy and chronic disease screening and management. J Immigr Minor Health. 2009;11(6):460–7.
36. Park OL, Kim SR. Integrated self-management program effects on hemodialysis patients: A quasi-experimental study. 2019;
37. Bhattad PB, Pacifico L. Empowering Patients: Promoting Patient Education and Health Literacy. Cureus [Internet]. 2022 Jul 27 [cited 2024 Jun 12];14(7). Available from: /pmc/articles/PMC9411825/
38. Pompey CS, Ridwan MN, Zahra AN, Yona S. Illness acceptance and quality of life among end state renal disease patients undergoing hemodialysis. Enferm Clin. 2019 Sep 1;29:128–33.
39. Hagger MS, Orbell S. The common sense model of illness self-regulation: a conceptual review and proposed extended model. Health Psychol Rev [Internet]. 2022 Jul 3 [cited 2024 Jun 12];16(3):347–77. Available from: https://www.tandfonline.com/doi/abs/10.1080/17437199.2021.1878050
40. Jansen DL, Rijken MJWM, Spreeuwenberg M, Grootendorst P, Dekker DC, Boeschoten FW, et al. Illness perceptions and treatment perceptions of patients with chronic kidney disease: different phases, different perceptions? Br J Health Psychol [Internet]. 2013 [cited 2018 Nov 1];18(2):244–62. Available from: http://onlinelibrary.wiley.com/doi/10.1111/bjhp.12002/abstracthttp://www.ncbi.nlm.nih.gov/pubmed/23126527http://www.nivel.eu
41. Opiyo RO, Nyasulu PS, Olenja J, Zunza M, Nguyen KA, Bukania Z, et al. Factors associated with adherence to dietary prescription among adult patients with chronic kidney disease on hemodialysis in national referral hospitals in Kenya: A mixed-methods survey. Ren Replace Ther. 2019 Sep 11;5(1).
42. Mollaoglu M, Candan F. Illness Perception and Hopelessness in Hemodialysis. [cited 2018 Oct 26]; Available from: https://www.peertechz.com/articles/illness-perception-and-hopelessness-in-hemodialysis.pdf
43. Cogley C, Bramham J, Bramham K, Smith A, Holian J, O'riordan A, et al. High rates of psychological distress, mental health diagnoses and suicide attempts in people with chronic kidney disease in Ireland. Nephrology Dialysis Transplantation [Internet]. 2023 Oct 1 [cited 2024 Jun 12];38(10):2152. Available from: /pmc/articles/PMC10539206/
44. Tsironi M, Tzavella F. Non Adherence Factors among Patients Undergoing Hemodialysis View project [Internet]. 2017 [cited 2018 Nov 1]. Available from: https://www.researchgate.net/publication/319968019

https://doi.org/10.56303/jhnresearch.v4i2.401